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**'An Exploration of Psychosocial Adjustment to Cardiopulmonary
Transplantation'**

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**Dissertation submitted to the University of Liverpool for the Degree of
Master of Science in Health Promotion in part fulfilment of the Modular
Programme in Health Promotion**

November 2005

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Declaration

The work presented for this Master of Science qualification is original and has not been submitted previously in support of any qualification or course.

Signed:

Miss Hilary Jane Cheater, BSc.

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List of Abbreviations

Abbreviation	Meaning
MDT	Multi-Disciplinary Team
PAIS	Psychosocial Adjustment to Illness Scale
B.T.S	British Transplantation Society
DH	Department of Health
NSCAG	National Specialist Commissioning Advisory Group
MDD	Major Depressive Disorder
PTSD	Post-traumatic Stress Disorder
NHS	National Health Service
LREC	Local Research Ethics Committee
PAIS-SR	Psychosocial Adjustment to Illness Scale – Self Report version
ANOVA	Analysis of Variance

Abstract

Aim

The aims of this assessment of needs research were: to explore psychosocial adjustment to cardiopulmonary transplantation among a sample of recipients; to gain an insight into the importance of psychosocial support for recipients; and to reveal any differences within demographic data, with regards to psychosocial adjustment.

Research Method

The research strategy employed was quantitative, and a cross-sectional study was undertaken, using the Psychosocial Adjustment to Illness Scale (Derogatis, 1983). A purposeful sample of 69 recipients were invited to participate in the research, and data was analysed using a variety of statistical tests within the Statistical Package for the Social Sciences (SPSS) Version 12.

Results

A total response rate of 47.8% (n=33) was achieved, with results indicating that 69.7% of recipients who participated in this research reflected 'maladjustment' or 'maladjustment within the clinical range' to cardiopulmonary transplantation. The clinical and statistical significance of results identified groups of patients at higher risk for maladjustment to cardiopulmonary transplantation, namely, those who were unemployed, those who lived further away from the transplant unit, and those who were between one and three years post-transplant.

Conclusion and Recommendations

These findings may be useful to the cardiopulmonary transplant unit where the research took place, and to other units and health care institutions throughout the United Kingdom. The results have the potential to influence policy decisions regarding health promotion interventions which may reduce the risk of maladjustment to cardiopulmonary transplantation. Furthermore, expansion of multi-disciplinary team services offered to cardiopulmonary transplant recipients may be considered. The findings may also have resonance with other chronic conditions with regards to the psychosocial support and intervention necessary to facilitate appropriate adjustment to illness and optimum patient recovery.

Chapter 1- Introduction

1.1. Title

'An Exploration of Psychosocial Adjustment to Cardiopulmonary Transplantation'

1.2. Terminology

According to Dew, et al. (2002), an on-going issue for the multi-disciplinary transplant team (MDT) is the maintenance of the recipients' psychosocial well-being over time, with the term 'psychosocial' being used to encompass virtually "every non-surgical or non-medical parameter of patients and their experiences" (Dew et al., 2000, p.240). This includes patients' ability to adjust psychologically, levels of behavioural and medical concordance, living conditions, and quality of life in a variety of domains, such as physical well-being, emotional well-being, employment, involvement with social and leisure activities, and quality of relationships with partner and/or family (Dew et al., 2000).

The construct of 'adjustment', according to Derogatis (1983), is not absolute. It is a continuing process which is established relative to some identified or implied group of people. As a concept, 'psychosocial adjustment to illness' attempts to review patients' perceptions of 'adjustment' to illness; looking at how well they are functioning within various multidimensional domains (Derogatis, 1983). This research makes use of the Psychosocial Adjustment to Illness Scale (PAIS), which includes an identified cardiac normative group. This normative group allows the construct of adjustment to be

measured with reference to the sample of cardiopulmonary transplant recipients from which this research is based (Derogatis, 1983).

The words 'cardiopulmonary' and 'cardiothoracic' relate to the contents of the chest. Therefore 'cardiopulmonary transplantation' involves transplantation of the heart, lung/lungs and heart/lungs (British Transplantation Society (BTS), 2003). For the purpose of this research, all three variations of cardiopulmonary transplantation are included.

1.3. Focus

The focus of this research is psychosocial adjustment to cardiopulmonary transplantation. There are many examples of psychosocial resources which may be available to cardiopulmonary transplant recipients. Such resources may include access to a qualified psychologist, psychiatrist, counsellor, social worker, various lifestyle consultants such as sexual therapists and employment co-ordinators, and various support networks such as social services and patient support networks.

Anecdotal evidence from recipients and informal discussions with transplant unit staff indicate that, at present, there are limited psychosocial resources available to transplant recipients, their families and staff at the unit where this research has taken place. Further anecdotal evidence gathered from the six adult cardiothoracic transplant units within the United Kingdom suggests inconsistency in terms of access to, and availability of, psychosocial provision for patients depending upon which transplant unit they attend for treatment. Anecdotal evidence at the unit where this research has taken place suggests that the majority of the emotional and psychological support of recipients falls

upon the specialist nursing staff and the two part-time transplant social workers, mainly in the outpatients department. Results may indicate an increasing need for broader psychosocial resource access within the MDT, due to the reportedly profound psychological problems encountered by patients and the increasing frequency in which the nurse specialists and social workers are approached with more complex problems. It has also been suggested by members of the MDT involved in the transplant process that, should the research suggest a need for improvements to the framework of care to better support cardiopulmonary recipients and enhance their quality of life, this would be embraced.

1.4. Background

Transplantation is often viewed as an effective procedure in preventing premature death (Burker, Evon, Galanko & Egan, 2005). However, contemporary health care in the United Kingdom and around the world continually strives to improve service provision and patient quality of life and to this end, clinicians and health promoting authorities are increasingly concerned not only to monitor physical outcomes of health care, but the psychosocial outcomes of medical intervention as measures of the quality of care provided (Sotile, 1996).

“Though often dismissed as ‘understandable’, distress is a treatable cause of reduced quality of life and poorer clinical outcome” (White & Macleod, 2002, p.377). Therefore it is suggested that the role of psychosocial resources in promoting health and improving patients’ morbidity and mortality in response to chronic illness must receive increasing attention, because it has been argued that, “there is no point in saving the body if, in the process, we destroy the soul” (Vance, 2001, p.272). According to Dew, et al. (2001),

psychosocial struggles are relatively common following organ transplantation, yet the general consensus has been that such difficulties improve with time.

It may be suggested that, currently, health advice and intervention available to transplant recipients in the United Kingdom focuses largely upon the biomedical model of health, with laboratory tests and biological variables that are affected by the transplant process. Wight et al. (1998) suggest that this biomedical approach to transplantation reflects the technical nature of the surgery and its maintenance. However, it is suggested that if this predominantly biomedical approach to the transplant care framework translates into poor psychosocial adjustment for recipients, it is in need of re-evaluation.

The Department of Health (DH) publications, including 'Saving Lives, Valuing Donors' (DH, 2003b) and 'National Heart and Lung Transplant Standards' (DH, 2002) along with the 'National Specialist Commissioning Advisory Group (NSCAG) Annual Report 2004-2005' (DH, 2005a) illustrate the importance of the MDT within the transplant care framework, and highlight the importance of addressing the psychological distress encountered by transplant recipients. However, anecdotal evidence gathered from the six cardiothoracic transplant units within the United Kingdom illustrate a general picture of inconsistency in care provision, long waiting times for access to psychosocial resources, and fears that not enough resources are being allocated to the psychosocial needs (to the detriment of the quality of life experienced) of transplant recipients.

It appears that researchers and health promoting authorities have not achieved an adequate understanding of psychosocial factors and their effects on transplant

recipients' quality of life, life satisfaction, and psychological, social and physical well-being before and after transplantation. The researcher has been unable to locate contemporary, comprehensive research into psychosocial adjustment to cardiopulmonary transplantation within the adult cardiothoracic transplant units in the United Kingdom. However, an ongoing study in Germany lead by Professor Buddeberg (Buddeberg, Gotzmann, Wagner-Huber, & Klaghofer, 2005) suggests that, thus far, about 50% of organ recipients show relevant psychosocial problems, which are often not addressed in the current post-transplant care approach.

1.5. Rationale

As transplantation is a treatment accompanied by life-long dependence upon potent anti-rejection medications, recipients are faced with an increased risk of adverse events that are life-altering and life-threatening (Pirsch, 1998). Therefore, it could be argued that transplant recipients may have greater need for psychosocial resources to support their ability to cope with post-transplant survival. Olbrisch and Levenson (1995) reported that, while the amount of empirical information on post-transplant psychosocial outcomes is growing, there has been poor understanding and interpretation of this information in order to make relevant and appropriate changes to transplant programmes. To this end, investigation of patients' psychosocial needs is greatly needed, as it is accepted that transplant recipients gain maximum benefit to their health outcomes and long-term survival when multi-disciplinary resources and medical care are coordinated effectively (DH, 2003b). The United States of America have led by example, with a strong framework of comprehensive medical and psychosocial care which is widely recognised as benefiting their transplant recipients, achieving greater survival

rates and improved psychosocial status over their British counterparts (Skotzko, Rudis, Kobashigawa & Laks, 1999).

From a health promotion point of view, this study is necessary for health professionals involved in transplantation within the United Kingdom, to consider the current framework of care offered to transplant recipients and perhaps make more informed and appropriate decisions about their priorities in terms of interventions that may be required for the comprehensive, holistic care of their patients. Any health promoting intervention based upon this research might lead to improved resource provision for transplant recipients and improved morbidity and mortality rates for recipients who, according to Burker et al. (2005), are often in desperate need of access to professional support and resources that extend beyond the skills of the cardiothoracic transplant surgeon.

1.6. Aims and Objectives

1.6.1. Aims

The purpose of this research was to utilise the Psychosocial Adjustment to Illness Scale (Derogatis, 1983) to inform health professionals and health promoters of psychosocial adjustment experienced by a sample of cardiopulmonary transplant recipients. Results from this research might indicate a need for re-evaluation of current provision within the transplant MDT to enhance the care provided at the unit where this research has taken place, and may be of interest to other units and health care institutions in terms of their provision for long-term transplant follow-up care. This study also aims to reveal any potential demographic associations, using statistical analysis upon the biographical data collected in conjunction with the validated PAIS (Derogatis, 1983).

1.6.2. Objectives

This research will:

- use a review of the literature, to explore transplantation and evaluate the importance of psychosocial input within the transplant care framework in meeting psychosocial needs of transplant recipients nationwide
- measure the psychosocial adjustment of a sample of cardiopulmonary transplant recipients using the PAIS
- explore the possibility of any relationship in terms of psychosocial adjustment to cardiopulmonary transplantation within demographic details obtained in conjunction with the validated PAIS.

1.7. Research Questions

The research aims to address the following questions:

1. Based upon the literature, to what extent have transplant recipients nationwide been supported through a multi-disciplinary framework of care which addresses psychosocial issues?
2. What is the psychosocial adjustment to cardiopulmonary transplantation, among a sample of recipients aged eighteen to forty at the time of their transplant?
3. Are there any statistically significant differences in terms of psychosocial adjustment experienced by this sample of cardiopulmonary transplant recipients, within demographic factors such as:
 - Gender
 - Access to provision (in terms of distance from transplant unit)

- Employment
- Years post-transplant
- Marital Status

Chapter 2 – Review of Literature

This chapter will explore cardiopulmonary transplantation from both the biomedical and the biopsychosocial context, and examine these different models of health. Furthermore, it will explore and evaluate the current provision available to cardiopulmonary transplant recipients nationwide.

2.1. Transplantation - The Biomedical Context

The first human heart transplant was carried out in 1967 by a transplant team headed by Christiaan Barnard. The patient died eighteen days later from bilateral pneumonia (Hoffenberg, 2001). The second heart transplant took place less than two weeks later, carried out by the same team, and the recipient survived for eighteen months. "It was the success of this operation that secured the future of heart transplants. Had it failed...further attempts would have been deferred for some years" (Hoffenberg, 2001, p.1478). According to Taylor, Watson, & Bradley (2005) early transplantation was hampered by issues including inexperienced surgeons without proper backup, graft rejection and infection, and as a result, short post-transplant survival was commonplace.

Transplantation is a procedure carried out with the aim of increasing life expectancy in individuals suffering from irreversible damage to organs, such as the heart and/or lungs, when death is expected to be within the next one to two years (Burker et al., 2005). In recent years transplant survival has improved significantly (DH, 2003b). Information received from United Kingdom Transplant (personal communication, 2nd August 2005) indicated that the longest surviving United Kingdom heart transplant recipient is 23 years

post-transplant; single lung is 17 years; double lung is 14 years, and heart/lung is 19 years post-transplant.

Because transplantation has seen many biological, surgical and technological advances, along with the continuing development of immunosuppression therapies and infection prevention techniques, there are increasing numbers of surviving patients (Taylor et al., 2005). However, Schein, Bernard, Spitz and Muskin (2003, p.xiii) suggest “the very success of modern biotechnological medicine has brought to the forefront its great weakness: the better we get at extending survival with serious illnesses, the more people we have with chronic illnesses”. Furthermore, “acute rejection, complications related to immunosuppressive protocols, and the development of chronic rejection continue to challenge the long-term success of heart and lung transplantations” (Reichenspurner, 2005, p.119).

2.1.1. Immunosuppression, Side-effects and Medical Procedures

Transplant recipients are dependent upon numerous medications for the rest of their lives, many of which are toxic and may cause unpleasant side effects (British Medical Association, 2004). The majority of these medications are ‘immunosuppressants’, which suppress the “individual’s innate biological ability to eliminate foreign organisms” (B.T.S, 2003, p.57). These medications are prescribed in an attempt at reducing the recipient’s ability to reject the transplanted organ/s (B.T.S, 2003). Since the immunosuppressive actions are not specific to the transplanted organ, recipients are at high risk from viral and bacterial infections (Taylor et al., 2005). Further medication is therefore required to attempt prevention of infections becoming life threatening, and in order to avoid the initial contraction of infections (Dressler, 2002). This often requires recipients to consider

lifestyle changes, for example, avoiding crowded places where infection may spread. Changes in body appearance due to immunosuppressants such as corticosteroids include cushingoid features (a rounded 'moon face'), acne, truncal obesity, excess hair growth and excess growth of gums around teeth (Serrano-Ikkos, Lask, Whitehead & Eisler, 1998). Consequentially, it is suggested that immunosuppression and medication regimens serve to increase psychosocial difficulties and therefore impact upon an individual's ability to cope as a transplant patient.

Recipients also endure numerous medical tests, and invasive procedures such as heart and lung biopsies to detect rejection, routine six weekly blood tests, and cardiac catheterization to detect changes in heart function (Dressler, 2002). More routine non-invasive procedures include lung function tests, x-rays, echocardiograms, electrocardiograms and blood pressure, and weight and diet monitoring (Dressler, 2002). According to Dew et al. (2002), recipients and their families reported that it took considerably longer than they expected to recover from the physical and emotional aspects of transplantation, and to fully adapt to the routine of post-transplant procedures, medications, side-effects and life-style restrictions. It is suggested that the constant medical stressors endured by recipients only serve to promote anxiety and fear. Therefore, it is essential that an investigation into psychosocial adjustment is fulfilled.

2.1.2. Transplantation - A Biomedical Model Approach?

For the last century, the dominant approach to health and disease in Western medicine has been the biomedical model of health (Gabe, Bury & Elston, 2004). This model originates from Rudolph Virchow's conclusion that all disease results from cellular

abnormalities, and has three main assumptions: all illness has a single underlying cause, disease is always the single cause, and removal of the disease will result in a return to health (Wade & Halligan, 2004). Hart (1997, p.10) argues that, "modern medicine is cure oriented. The primary goal is treatment and medical consultation starts with the description of symptoms". It is suggested that this approach aims only to solve the immediate problem of disease, and does not take into account initial causes of illness, possible preventative measures, and treats the illness rather than the patient (White, 2005).

Transplantation, a procedure which has the aim of eradicating disease and alleviating physical symptoms, followed by the management of rejection and infection, falls within the biomedical approach to health (Wight et al., 1998). According to McLaren (1998), despite the undoubted success of the biomedical model in curing diseases and increasing human survival, many researchers have highlighted its deficiencies, characterizing it as 'reductionist'. Deep (1999, p.497) argues that "the biological model of health and disease is outdated and inadequate", and as Fremont and Bird (1999) suggest, the biomedical approach to health does not consider psychosocial aspects of illness, and their influence upon an individual's perception of their health, illness, and recovery process. It is suggested that due to the nature of transplantation, with its attendant high levels of psychosocial distress (Napolitano et al., 2002), one might refute this reductionist, biomedical approach as unsatisfactory for cardiopulmonary transplant recipients and their families, and an exploration of a more holistic approach to patient care is required.

2.2. The Biopsychosocial Model

The biopsychosocial model of health, proposed by psychiatrist George Engel (1977), stresses the importance of a holistic approach to medicine and health. It considers factors outside the biological process of illness, and attempts to understand health and disease in the context of the individual as a whole (Engel, 1977). In this approach, a person's social context and psychological well-being are key factors in their illness and recovery, along with their thoughts, beliefs and emotions about illness (White, 2005). White (2005) is severely critical of the failure of modern medicine to treat the patient not the disease, and its neglect of psychological and social factors in the treatment of the individual. Engel's model attempts to solve this problem and it is considered the more appropriate approach when dealing with transplantation - which involves not only the biological aspect but many emotional, social, psychological and spiritual aspects as well (Dew et al., 2002).

2.3. Biopsychosocial Issues in Transplantation

According to Smeritschnig et al. (2005), due to improving survival rates for cardiopulmonary transplantation, more consideration is now being given to quality of life, rehabilitation and re-integration into society for recipients. Furthermore, as Cicutto et al. (2004) suggest, one of the goals of transplantation is to help the recipient improve their physical, mental and social functioning. Transplantation is not curative, and recipients and their families face innumerable post-operative physical, social and psychological stresses (Serrano-Ikkos, Lask, Whitehead, Rees & Graham, 1999). American research by Stukas et al. (1999) revealed that 58% of recipients experience pronounced psychiatric distress, and/or diagnosable psychiatric disorders, following their transplant, although it has to be acknowledged there was no comparable data taken pre-transplant

and this is a limitation of the research. However, as Smeritschnig et al. (2005) argue, whether recipients experienced psychosocial maladjustment before their transplant, or whether these difficulties manifested afterwards is questionable. Stukas et al. (1999) suggest that transplantation is an incredible trauma for both body and mind, and consequentially the psychological, social, emotional and spiritual impacts of this process are inevitably multiple.

One study by Baines, Joseph and Jindal (2002) grouped emotional responses to transplantation into three recurring themes: fear of rejection (of the organ), fear of the loss of the organ despite successful transplant; and psychological integration of the newly acquired organ. The two former themes of fear have, at their root, a sense of uncertainty about the future, and prompt worry, anxiety and a feeling of loss of control (Edelmann, 2000). Regarding the latter, there are many dimensions to the transplant process, but the most poignant and compelling is that cardiothoracic transplantation involves the death and loss of one person, in order to give the opportunity of life to another (DH, 2003b). It is therefore suggested that the emotional and psychological impact for the recipient who has accepted the organ of another person is inevitably complex.

It must be acknowledged during this examination of literature that, although many transplant recipients suffer from psychological problems (Dew et al., 2002), this may not be directly attributable to the transplant process (Smeritschnig et al., 2005). Medical illness of any kind causes stress, producing anxiety about prognosis, treatment, disability, quality of life and interference with social roles and relationships (Schein et al., 2003). Chronic illness can lead to changes in personality where pre-existing negative

traits are exacerbated, and this may lead to patients becoming negative, bitter and resentful (Schein et al., 2003), it is suggested that the biomedical reaction to this emotional difficulty, would be to prescribe medication, but as Bowman (2001, p.261) argues, there is a clear ethical issue, in prescribing psychotropic medication "...to patients whose emotional reaction is a direct result of an experience that they need to understand and to which they must adapt", and therefore an increased psychosocial approach is necessary.

2.3.1. Health Care Orientation

According to Schein et al. (2003) patients are expected to accept doctors' explanations and comply with their instructions without question. Furthermore, "professional dominance is revealed in practitioners' delegitimization of the knowledge and experience of people who have lived with a chronic illness" (Paterson, 2001, p.574). Patients who may have previously been compliant and trusting of health professionals and of therapeutic regimes, may turn away from all aspects of adherence out of fatigue and despair - this is especially so for patients who have endured many defeats and disappointments (Schein et al., 2003). This indicates that the psychosocial functioning of cardiopulmonary transplant recipients may also be affected by the doctor-patient relationship. The doctors' approach to symptoms, the patient's life, the emotional and behavioural advice offered, and the empathy and support conveyed may all contribute to functioning (Schein et al., 2003). It is argued by Hart (1997), that when doctors act purely as 'body mechanics,' they disregard spiritual welfare, are oblivious to harm that medical treatment itself may inflict, and are ignorant of the wider social environment which impacts patient self-care, and well-being. However, chronic illness care often requires patients to become autonomous, integral members of the health care team

(Schein et al., 2003), and in the context of transplantation, responsible for adherence to prescribed medication regimes and even more complex aspects of their care. One of the DH's main aims within the 'NHS Improvement Plan' (DH, 2004b) is a biopsychosocial, patient-centred approach to healthcare. Although it can be argued that some recipients may not wish to be involved in patient-centred care, the DH, (2004b) suggest that most will want to share responsibility for managing their own condition within an agreed care plan, in partnership with professional staff.

Medicine invests a great deal of energy and ingenuity in developing biomedical treatments however, it is ineffective to have state-of-the-art medical technology and procedures if patients then fail to implement the prescribed treatments (Schein et al., 2003). Despite its absolute contraindication to transplant survival, non-adherence to medication regimes among cardiovascular patients ranges from 25% to 50% (Burke, Dunbar-Jacob & Hill, 1997). Furthermore, current literature suggests that psychosocial issues arising from the side-effects of medication may result in patients abandoning their regime (Christensen, 2004). A medical consultation may not have time to discuss emotions and concerns about pain and suffering, or to explore how misinformation may create anxiety leading to non-compliance (Schein et al., 2003). It is acknowledged that health issues over the past decade have changed rapidly, and the paucity of contemporary research requires renewed investigation. Therefore, it is suggested that investigation into the impact of health care orientation and beliefs upon psychosocial adjustment is imperative.

2.3.2. Employment and Financial Issues

Winsett (1998) suggests that transplant recipients should be encouraged to return to work if at all possible, as they are more likely to better adjust to transplantation if they are employed. According to Seedhouse (1997), withdrawal from the work role due to illness inevitably limits opportunities for supportive interaction, whilst Reyes et al. (2004) revealed an association between employment status and fatigue in cardiopulmonary transplant recipients, with a sense of control and continued physical activity relating to work roles and hence, benefiting patients in terms of lessened fatigue. Finally, research by Chisholm (2002) found that employed transplant recipients were more likely to adhere to medication and therapy than recipients who were unemployed.

For many recipients, however, physical, medical, social and emotional issues impact attainment of paid employment post-transplant (Cicutto et al., 2004). Quite apart from the physical traumas visited upon the body, by medications and invasive procedures, regular out-patient and in-patient treatments often create circumstances where employment, or continued employment becomes difficult, and often impossible due to frequent absences or potential absence from work (Salyer, Flattery, Joyner, & Elswick, 2003). Furthermore, Cicutto et al. (2004) found that recipients who had never attained employment feared the loss of state benefits, and were anxious regarding their ability to work under the perceived inflexibility in hours and working duties. Whilst Dew et al. (2002) argue that the potential loss of state benefits place strains upon transplant recipients in terms of fears about medication costs, attending hospitals, GPs and clinic costs, housing costs and costs of care and independence, it is also acknowledged that awareness and understanding of the complex rules surrounding state benefits and employment is poor (Dewson, Davis & Loukas, 2004). Furthermore, according to Cicutto

et al. (2004), these circumstances actively discourage transplant recipients from attempting employment after transplantation. It is suggested that when transplant recipients are refused private medical insurance, and are not exempt from prescription charges, the above factors amount to an extensive barrier to attainment of paid employment. Consequently, investigation into the impact of employment upon psychosocial adjustment is greatly needed.

2.3.3. Domestic, Family, and Gender roles

It is suggested that additional psychosocial issues for the transplant recipient may include the altering of roles within family or social scenarios, from that of a chronically ill patient to an unclear, ill-defined new role. Furthermore, anecdotal evidence suggests that patients who face sudden onset cardiopulmonary illness, such as cardiomyopathy, may experience limited ability to perform domestic tasks and employment roles post-transplant, which they may have been fully able to fulfil previously. As Bunzel, Laederach-Hofmann and Schubert (1999) found, transplant recipients encounter difficulties in their interpersonal relationships as well as social functioning limitations, along the domains of failure to return to work, and restrictions in leisure and domestic roles. Findings from another American study by DeMaso, Kelley, Bastardi and Blume (2004) further support this ideology by concluding that family functioning is an influential determinant of the emotional adaptation of cardiopulmonary transplant recipients, and familial support is also essential for the maintenance of good health and adherence to medication.

It has been speculated by Schein et al. (2003) that women are disadvantaged relative to men, because their roles expose them to more chronic stress. It is suggested that this is

particularly true when women adopt traditional role situations. It has also been suggested that women are more likely to suffer from psychological impairment and emotional distress than men, when illness occurs (Taylor, 2003). Furthermore, it has been suggested that female transplant recipients are at greater risk for psychosocial maladjustment and elevated symptoms of emotional disturbance, just as they are in the general non transplanted population (Dew et al., 1996). No current literature, has disputed this suggestion. In conclusion, as Cohen, Littlefield, Kelly, Maurer and Abbey (1998) report, evidence suggests that social support from family and friends reduces psychosocial maladjustment risk therefore renewed investigation into the impact of domestic roles, family functioning and gender differences upon psychosocial adjustment is required.

2.3.4. Partnerships and Sexual Relationships

It is proposed that the transplant experience can cause disruption in various domains of relationship functioning. According to Kurz (2001) the marital relationship is vital, since the most common support person for a transplant recipient is a spouse, and it has been revealed that spousal adjustment is associated with the adjustment of the recipient. However, Dew et al. (2002) reported that patients and their partners can be dismayed that pre-existing relationship problems may be exacerbated through the transplant experience, yet conversely, the stress of the whole process can actually serve to temporarily hold some relationships together. Issues which impact on relationships, include the emotional and psychological effects of living with a long-term condition on the individual and their carer. "These can include stress, depression, loss of self image and cognitive/behavioural issues, which may lead to relationship breakdown if not addressed" (DH, 2005b, p.11).

Sexuality is an important aspect of quality of life (Taylor, 2003) but according to Smeritschnig et al. (2005) the high prevalence of impotence among male transplant recipients is remarkable, with 39% of male transplant recipients reporting high incidences of difficulties with sexual functioning. It is suggested that, within the transplantation population, a number of issues interfere significantly with sexual capacity and with ones' self-image as a sexual being. Schein et al. (2003) illustrated that surgical procedures involving scars, and altered body image due to medication, along with the simple fact of being ill, generates insecurities and sexual performance anxiety. Further impedance of sexual satisfaction may occur due to the physical side effects of medications, diabetes, or previous diseases (Smeritschnig et al., 2005). Such difficulties highlight the need for further inquiry into the impact of marital status upon psychosocial adjustment.

2.3.5. Years Post-Transplant

Edelmann (2000) suggests that the adjustment process to chronic illness can be likened to the bereavement process. The various stages which a patient may pass through include: a stage of crisis, characterized by shock and bewilderment; the encounter reaction stage, characterized by loss, grief and helplessness and despair; the retreat phase, characterized by denial or retreat; and finally, facing up to reality, characterized by adjustment and acceptance (Edelmann, 2000). Dew et al. (2000) support this theory, by reporting that anxiety disorders have their onsets largely during the first years after the transplant, and 25% of heart transplant recipients experience major depressive disorder (MDD) during the first three years after their transplant. Post-traumatic stress disorder (PTSD) has also been found in heart transplant recipients, indicating a failure to adjust to the experience (Stukas et al., 1999). An American study by Salyer et al. (2003)

suggests that psychosocial adjustment, although imperfect, is better amongst the longest survivors. Although recipients continue to experience work problems, financial burdens, family role changes, lifestyle changes and side effects to the immunosuppressive therapy, it was concluded that, over time, recipients adjust to the changes in their lives occurring as a result of the transplant and showed psychological functioning within the normal range. However, it may be argued that this normality of functioning is attributable to the greater level of psychosocial support prescribed by transplantation programmes in the private health care system within the United States of America (DeMaso et al., 2004). To this end, investigation into the relevance of survival years post transplant upon psychosocial adjustment is considered necessary.

2.3.6. Social Environment and Access to Provision

The onset of chronic illness may cause social isolation, resulting in the withdrawal of family and friends, the normal social support network, because they feel unable to deal with the ill person (Edelmann, 2000). The patients' social functioning is an important determinant of emotional adjustment (Schein et al., 2003). In addition, psychological distress may hinder the individual's ability to work or engage in social activities, hence further undermining that individual's quality of life (Edelmann, 2000). "Physical debilitation or other difficulties may prevent the individual from carrying out normal leisure time activities...a less positive adaptive posture may find the individual showing a significant loss of interest as well as being impaired in his/her ability to perform them" (Derogatis, 1983, p.12).

Napolitano et al. (2002) suggest that cardiopulmonary transplant recipients are usually allocated to units according to geographical location, and these geographical catchment

areas can be extremely large with patients often being widely dispersed within them. As Dew et al. (2004) report, the efforts of the transplant MDT to address psychosocial issues is often hampered due to many recipients residing long distances from the transplant programme. One of the key aims of the National Specialist Commissioning Advisory Group (NSCAG) is to ensure that its services are accessible to all NHS patients (DH, 2005a). NSCAG further state that, "it is important to ensure that patients remote from the treatment centres are not served less well" (DH., 2005a, p.5). It is suggested that in the context of psychosocial adjustment to cardiopulmonary transplantation, this difficulty may be partly overcome by referral to local services. However, these services may not possess transplant specific knowledge and thus may not address patient needs appropriately (Carlson and Bultz, 2003). It is therefore suggested that investigation into recipient's social environment and access to their transplant unit is needed.

2.4. Current Provision of Services within the Transplant MDT

NSCAG is a nationally funded body within the Department of Health. It was established in 1996, following the Chief Medical Officer's review of commissioning arrangements for specialist services for rare conditions (DH, 2005a). Specialist services which are designated and funded nationally under the auspices of NSCAG usually have a patient caseload of below four hundred, and cardiopulmonary transplantation in both adults and children is among these (DH, 2005a). To illustrate this low caseload, the number of cardiopulmonary transplants performed in the financial year of 2004-2005 comprised: twelve heart/lung transplants; one hundred and forty hearts; and ninety-eight lung/s (DH, 2005a). These statistics are described as being "among the best in the world" (DH, 2005a, p.12) with increasing numbers of cardiopulmonary transplants being carried out.

Each year, transplant units apply to NSCAG for the funds required for the following year. This can include additional funding to take into account instances such as increased volume of patients, and it can consider clinical developments and proposed service developments, that have been outlined as priorities by the individual transplant unit.

In addition to the financial role of NSCAG within cardiopulmonary transplantation, the publication of evidence-based 'National Heart and Lung Transplant Standards' were produced, by a 'standards development group' including members from all the UK cardiopulmonary transplant units. These standards were formed in an attempt to improve clinical care, after a review of facilities and supporting departments involved in the investigation and management of transplant recipients (DH, 2002). The biomedical approach is highlighted by the fact that thirteen out of the fifteen members in this development group were physicians, surgeons or medical advisors to the Department of Health.

Information from NSCAG (personal communication, 25th July, 2005) revealed that the transplant standards are 'the ideal' and that psychosocial input is seen as an intrinsic part of transplant patient care. The BTS (2003) define the National Heart and Lung Transplant Standards as "an agreed defined set of procedures which establish the level which any service must achieve to become accredited" (B.T.S, 2003, p.59). The following paragraphs contain observations regarding the National Heart and Lung Transplant Standards (2002) document.

Standard 1.4 (DH, 2002, p.7) states that, "a range of psychological and social support services should be offered to meet the needs of patients and carers", and that these

services should be made available by the transplant unit. However, standard 2.1 (DH, 2002, p.9) suggests that, in meeting this aim, the MDT within the cardiopulmonary transplant care framework should comprise: the surgeons; cardiologist(s); chest physician(s); anaesthetists/critical care physician(s); the transplant histopathologist(s); microbiologist(s); virologist; radiologist; transplant nurses; recipient co-ordinators; physiotherapist; dietician; and social workers. Although it may be argued that some members of the team are able to address some psychosocial aspects of transplantation, the National Heart and Lung Transplant Standards' suggested composition of the MDT is predominantly biomedical. Furthermore, standard 1.1 (DH, 2002, p.7) indicates an ideal of 'comprehensive support' for transplant recipients. It is argued that comprehensive support should include more psychosocial care in order to enhance the cardiopulmonary transplant care framework and the MDTs caring for transplant recipients across the nation.

Interestingly, standard 2.8 (DH, 2002, p.41), outlines the paediatric MDT framework in much the same way as for adult recipients, with two exceptions - child psychiatrists and psychologists are considered as essential roles within the MDT. This raises a question about why there are differences between adult and paediatric MDT frameworks of care. Furthermore, Sotile (1996, p.7) stated that "...a growing legion of researchers are calling for aggressive expansion of the psychosocial component of traditional medical care." However, nine years on, this is still not reflected.

The Department of Health (2003b) document, 'Saving Lives, Valuing Donors: A Transplant Framework for England' acknowledges the challenge of designing services around the needs of patients. It identifies the roles that the Government, and individuals,

can play in improving the clinical outcomes and quality of life of people who receive organ transplants. Furthermore, it acknowledges that transplant units vary widely in their levels of activity, staffing and facilities (DH, 2003b). This document also acknowledges the challenge of ensuring that staff with appropriate skills, are recruited, well-led and supported in delivering high quality care (DH, 2003b).

The Department of Health (2003b) also suggests that creating a 'patient-centred' transplant service, and designing services around the needs of recipients is necessary to raise the quality of the transplantation process, "...so that the psychological needs of the donors, donor families and recipients are met" (DH, 2003b, p.15). A further objective aims to ensure that all members of the MDT "understand the psychological impact of the transplantation process", and are trained to provide information, advice, counselling and support to recipients (DH, 2003b, p.15). It is suggested that the framework is lacking on patient-centred transplant services as, although it highlights the general problems and issues, it does not give due credence to the myriad problems faced by the recipient, nor does it give a real framework for action as to how these issues will be solved.

The BTS (2003) highlight the importance of uniformity of services for transplant recipients across the nation. However, some units currently offer increased psychosocial support whilst others do not. Anecdotal evidence was gathered by the researcher, from the five adult cardiopulmonary transplant units in the United Kingdom, about psychosocial services included in their MDT's. This evidence revealed that one unit had a full time psychologist as part of the MDT and available to recipients at that unit, and a further unit employed a part-time psychologist. However, the remaining three units did not have a psychologist attached to the MDT within the transplant programme. All units

adhered to standard 2.1 of the National Heart and Lung Transplant Standards (D.O.H, 2002) regarding the inclusion of a social worker. In contrast to the adult units, the London children's transplant unit also incorporated a full time psychologist as part of their MDT.

As Schoonover (2002) suggests, the psychologist is a vital part of the transplant MDT and acknowledges the fact that psychosocial issues surrounding cardiopulmonary transplantation are complex, and it is comforting for patients to be able to approach a mental health professional who is knowledgeable about the process of transplantation. Furthermore, it is suggested by Schoonover (2002) that preventative psychological care is vital because the emotional preparation that an individual has, and the attitude they approach transplantation with, is directly linked with their long-term adjustment. She points out that ideally a psychologist should be part of the MDT rather than waiting until there is a problem, where waiting lists become a barrier to effective intervention.

A further issue for the transplant team, as the DH (2004a) outline, is the difficulty in recruiting health professionals who are willing and/or able to specialise in certain areas of transplantation. However, Carlson and Bultz (2003), argue that psychosocial distress can only be treated by qualified, knowledgeable health professionals with experience of psychosocial care within certain chronic illness groups. Furthermore, geographical dispersion of patients increases the difficulties of implementing psychosocial support for patients, as there are problems seeing patients face-to-face on a regular basis in order to provide ongoing care and as Dew et al. (2002) argue, this challenge is greater when patients live long distances from the transplant centre. Finally, it must be acknowledged that the power of decision making and the politics of critical care settings may hinder the

recruitment of non-clinical MDT staff. As Dew et al. (2000) suggest, this may reflect attitudes towards psychosocial interventions and their usefulness to patients, and also reflects the narrow view that psychosocial service provision is beyond the responsibility of the programme.

2.4. Concluding Remarks

According to Napolitano et al. (2002) high levels of psychosocial distress may be associated with adverse health outcomes and poor post-transplant psychosocial adjustment. Therefore, understanding the adaptation and coping of these patients to such a stressful life experience may have important implications for long-term graft and recipient survival (DeMaso et al. 2004). This Review of the Literature has informed this research by discussing the advantages of a biopsychosocial approach to cardiopulmonary transplantation, and as Schein et al. (2003) argue, modern medical care cannot be delivered by physicians alone because, in this complex environment, a large number of professionals are needed to address different aspects of patient care. However, as Kurz (2001) illustrates, the existing literature mainly focuses on surgical techniques, medication regimes physiological changes, and physical complications and, although medicine has acknowledged the advantages of the biopsychosocial model as the 'ideal' in patient centred care, there is a paucity of modern research examining psychosocial adjustment to cardiopulmonary transplantation. Skotzko, et al. (2001) found overwhelming support among some health professionals for the implementation and maintenance of comprehensive psychosocial services within transplantation programmes, but it is evident that from a health promotion point of view, a needs assessment of psychosocial adjustment to cardiopulmonary transplantation is required

in order to gather the information required to consider a change beneficial to the health of the transplant population (Stevens & Gillam, 1998).

Chapter 3 - Methodology

This chapter will reflect upon how the method was designed to answer the research questions (Chapter 1, p.7). It will outline and justify the changes made to the original research strategy, and will critically reflect upon the final research design.

3.1 Research Strategy

In accordance with the Research Governance Framework for Health and Social Care (DH, 2003a), ethical approval was sought by the researcher via an application to the Local Research Ethics Committee. Originally, the researcher advocated a quantitative and qualitative approach to data collection to fully explore the original research questions, in particular:

- What are the perceived psychosocial needs of this sample of recipients, and in what ways do they feel that their needs are being met?

This approach is supported by Bryman (2000), who argues that combining quantitative and qualitative research provides a more accurate picture of social reality. Therefore, the researcher believed that, in order to fully address the above question, qualitative data collection in the form of semi-structured interviews should be employed. Furthermore, the researcher produced an extra set of questions, designed to gather transplant specific data (Appendix 1, p.107), the purpose of which was to generate variables for comparison, in an attempt to reveal potential risk factors for psychosocial maladjustment. The validated quantitative research tool originally chosen was the SF36

Version 2 (Medical Outcomes Trust, 1998), which is a multi-purpose health survey with thirty six questions, yielding an eight scale profile of health and general 'quality of life' (Appendix 2, p.112).

The original research design was altered for a number of reasons. Firstly, after reflection and further study, the researcher felt the above question and its desire to explore perceived 'quality of life' was enormously difficult to define and quantify. According to (Bowling, 2001), 'quality of life' is an often misused term, the concept of which is hard to define, and the measurement of which is inevitably difficult. Secondly, the researcher felt that the study had developed a larger focus than was originally intended, with a design better suited to academic work at a higher level and with a broader remit. Thirdly, the original application for research was rejected by the Local Research Ethics Committee (LREC), due to their preference for a solely quantitative approach to research, only allowing the use of a validated data collection tool. To this end, the emphasis on 'quality of life' was removed from the research, and the focus was narrowed along with refinement of the research aims and questions.

The research question pertaining to the perceived psychosocial needs of the sample (outlined earlier) was replaced with a question aiming to explore the influence of demographic factors upon psychosocial adjustment to cardiopulmonary transplantation (Chapter 1, p.7). Hence, the researcher decided not to use the SF36, due to its focus on 'quality of life'. Furthermore, it was decided that the generic nature of this research tool was not appropriate and that a more disease and treatment group specific research tool was needed.

The research strategy was altered to quantitative data collection only and, as Bryman (2001) suggests, the social world can be studied objectively in much the same way as the natural sciences by quantitative research. The researcher selected the PAIS (Derogatis, 1983), a tool which is designed to assess the quality of a patient's psychosocial adjustment to a current medical illness, or its residual side effects (Appendix 3, p.117). It would be used to explore the psychosocial adjustment of a sample of cardiopulmonary transplant recipients, as outlined within the third research question (Chapter 1, p.7), within demographic factors such as:

- Gender
- Access to provision (in terms of distance from transplant unit)
- Employment
- Years post-transplant
- Marital status

A further application was submitted to the LREC, again without success. The research was refused because the demographic, transplant specific questions were considered inappropriate and the recipient was "not qualified to answer them" (Personal communication, 16th February, 2005). After extensive negotiation with the Chairperson of the LREC, the researcher was allowed to use two of the original fifteen transplant specific questions (Appendix 4, p.125). These were:

- 1) How far do you live from the hospital?
- 2) How long has it been since your transplant?

The researcher felt that it was important to explore the impact of these factors, along with the general demographic data obtained by the PAIS, because it is one of NSCAG's main aims to, "ensure that patients remote from the treatment centres are not served less well than patients living nearer to centres" (DH, 2004a, p.4). Furthermore, as Dew et al. (2000) report, time post-transplant can be a major factor in the development of MDD and PTSD and as Bowling (2001) suggests, many disease specific research tools are criticised for being too narrow in focus, neglecting the measurement of variables which may be relevant to the outcome of research.

The third application, to the LREC was successful and the research strategy as outlined above was approved. Complete ethical approval was gained in April 2005 and, upon receipt of LREC approval, (Appendix 5, p.126), the Hospital's Research and Development department issued an honorary contract in adherence with the Research Governance Framework (DH, 2003a). Approval had previously been gained from the University of Chester and data collection commenced in May 2005.

3.2 Research Method

Due to transplant recipients being widely dispersed geographically (Dew et al., 2004), it was decided that a cross-sectional postal survey method would be adopted, as it is cheap, quick and easy to administer (Bryman, 2001). For this reason, it was advantageous that all of the recipients could be approached at the same time. This method also allows anonymity of responses, which is preferable when sensitive information is requested (Blaxter et al., 2001). In practice anonymity was offered, and no member of the MDT at the transplant unit was aware of who returned questionnaires for this research. Bowling (2001) suggests this method is preferable to others, in eliminating

interviewer bias, as it allows the participant to record honest answers, in private, minimising the feeling of the need to justify responses or be influenced by the presence of an interviewer. It was hoped that this approach would maximise the reliability of data.

Some disadvantages of this method, according to (Bryman, 2001), include a low response rate as there is no incentive for the recipient to return the questionnaire, a lack of desire to participate, and a lack of understanding of the completion requirements. Furthermore, if the researcher is unable to control the environment in which the questionnaire is completed, and is not available to answer queries, a danger of receiving inaccurate information may ensue (Bell, 1999). After consideration of the advantages and disadvantages of the cross-sectional postal survey method, the researcher concluded that this method was the most appropriate in order to address the research questions and was therefore employed. The researcher attempted to limit the disadvantages of this method by addressing the above issues, and formulating an appropriate framework of patient approach and information delivery, as outlined below.

3.3 Research Tools

3.3.1. The PAIS-SR

Due to the use of the postal survey method, the self-report version of the research tool, the PAIS-SR was utilised (Appendix 3, p.117). According to Derogatis (1983, p.7), the PAIS is appropriate for assessment of any medical condition which “has an identifiable psychosocial component, and which is of sufficient severity to impact measurably on the psychological and interpersonal integrity of the patient.” According to (Stukas et al., 1999), 58% of the cardiopulmonary transplant recipients in their study experienced

pronounced psychological distress and/or diagnosable psychiatric disorders. Furthermore, Bunzel et al. (1999) found that transplant recipients encounter difficulties in their interpersonal relationships as well as social functioning. Therefore, the researcher felt this particular tool would be effective in addressing the research questions. The PAIS-SR reflects psychosocial adjustment to illness via seven primary domains of adjustment. These domains are as follows:

I. Health-Care Orientation

This section of the questionnaire has eight questions designed to address the nature of the respondent's health care beliefs and whether they function to promote positive or negative adjustment to illness and treatment (Derogatis, 1983). Patient attitudes, quality of information, and the nature of expectancies about their condition and its treatment are all addressed within this domain.

II. Vocational Environment

This section of the questionnaire has six questions designed to reflect the impact that illness may have on vocational adjustment. The term 'vocation' is flexibly defined to indicate work, education or home whichever is more appropriate (Derogatis, 1983). These questions address job performance, lost time, job interest and a number of other variables that are associated with vocational adjustment.

III. Domestic Environment

This section of the questionnaire has eight questions, oriented towards illness induced difficulties that arise in the home or family environment. It assesses problems in adaptation experienced by the patient and their family in response to the patient's illness

(Derogatis, 1983). Questions measure a number of aspects of family living, including the financial impact of illness, quality of relationships, the effects of physical disabilities, and family communications.

IV. Sexual Relationship

This section of the questionnaire has six questions designed to provide a measure of any changes in the quality of sexual functioning or relationship associated with the patient's illness (Derogatis, 1983). Questions are designed to be presented in a progressive sequence, beginning with a focus on quality of relationship and moving toward more specific issues of sexual functioning.

V. Extended Family Relationship

This section of the questionnaire has five questions devoted to measuring any disruption in relationships with an extended family network that arises due to the illness experience. The framework of 'typical interactions' is used to assess any negative impact of the illness upon variables such as interest and interaction, communication, and quality of relationships with extended family members (Derogatis, 1983).

VI. Social Environment

This section of the questionnaire has six questions reflecting the status of the patient's current social and leisure time activities and the degree to which they have suffered restriction of these activities as a result of their illness and its residual side effects. Activities are partitioned into 'individual', 'family' and 'social' categories with questions focussing on interest and actual behaviour in each category (Derogatis, 1983).

VII. Psychological Distress

This section of the questionnaire has seven questions covering various aspects of psychological distress, and is designed to measure 'dysphoric thoughts' (Derogatis, 1983) and feelings that accompany the patient's illness or are a direct result of the illness and any associated issues. Major indicators of psychological distress such as depression, hostility, anxiety, reduced self-esteem and body image are measured in this domain.

The PAIS tool includes its own scoring framework, which was used within this research to generate t-scores (Derogatis, 1983). Each question on the PAIS-SR is allocated a score of 0-3 depending upon the response. The total of the scores is then converted into standardized t-scores by referring to the cardiac patient norm table (Derogatis, 1983, p.53). Standardized t-scores are useful as they have a mean of 50 and a standard deviation of 10. This enables direct comparison between the published cardiac norm, and the sample used in this research. Furthermore, it enables direct comparison between domains within the PAIS-SR tool.

The t-scores were then interpreted into the following categories:

- t-scores less than 60 are from patients who are considered 'well adjusted'.
- t-scores greater than 60 are from patients who are considered as 'maladjusted' and therefore marginally clinical.
- t-scores greater than 63 are from patients who are considered as 'maladjusted, clearly within the clinical range'.

(Derogatis, 1983)

The description of the patient as 'maladjusted' or 'maladjusted within the clinical range' serves as an aid to health professionals in identifying patients who "might benefit from increased attention to the psychosocial elements of their illness" (Derogatis, 1983, p.33), in order to improve their health and well-being.

3.3.2 Additional Questions

In addition to the PAIS-SR, the respondent was presented with two additional questions, detailed previously (Appendix 4, p.125). These questions were of specific relevance to transplant recipients and would not be gained simply using the PAIS-SR questionnaire.

3.4 Reliability and Validity of the PAIS instrument

According to Derogatis (1983) the PAIS is a widely used instrument and is applicable for use within many disease and treatment groups. Feurer et al. (2004) reported that the PAIS instrument has been statistically proven to be both reliable in attaining consistent measurement of variables, and is also validated as measuring what it claims to measure. Furthermore, Feurer et al. (2004) defend the reliability and validity of the PAIS, and propose that it is internally consistent when applied to an organ transplant population, again supporting its selection for use in this research.

3.5 Sampling Strategy and Recruitment

The sampling frame used for this research was the Transplant Unit's list of recipients at April 2005. A purposeful sample of N=69 were listed as potential participants, according to the inclusion criteria of aged eighteen (because of issues with consent) to forty years old, and who are at least six months post-operative. The inclusion criteria aimed to explore the 'young adult', which has been defined by Haire and Roll (2004) as below 40

years of age. It has been reported that older recipients are more likely to have degenerative health problems, and are more likely to be resigned to ill health with associated increased levels of depression (Wight et al., 1998). The researcher felt that this might skew the distribution of scores and might not be representative of the transplant population. Furthermore, the transplant MDT requested that the inclusion criteria of at least six months post operative be adhered to, due to the possibility of causing psychological distress to recipients recently coming to terms with such a major life event, which was felt to be less likely after this period.

Participation was not assumed, and the first stage of data collection was the invitation to participate. The materials presented to the recipient included: a covering letter (Appendix 6, p.127); a patient information sheet (Appendix 7, p.128); a consent form (Appendix 8, p.132); a stamped addressed envelope; and the general practitioner letter (Appendix 9, p.133). Collectively, this detailed the research aims, explained the study design and invited the recipient to participate.

The second stage of the research was the distribution of questionnaires to consenting recipients. The materials sent to participants included: a 'thank you for taking part' letter (Appendix 10, p.134); the PAIS-SR questionnaire (Appendix 3, p.117); a stamped addressed envelope; and the two additional questions (Appendix 4, p.125). After this stage was completed, the researcher was not aware of the identity of the recipient who completed and returned questionnaires. It is acknowledged that using this two-stage approach may reduce the response rate, but the benefit of allowing participants to give informed consent to receive a questionnaire demonstrates greater respect for autonomy than assuming participation (Blaxter et al. 2001).

3.6 Ethical Considerations

Blaxter et al. (2001, p.158) state that "the conduct of ethically informed social research should be a goal of all social researchers" and, with this goal in mind, the researcher anticipated a number of ethical considerations relevant to this research. Voluntary participation was of paramount importance throughout this research. Respondents may feel pressurised to participate in projects where a researcher needs to collect a certain amount of data to complete their study (Blaxter et al., 2001). In an attempt to minimise this, the researcher ensured that the materials posted encouraged recipients to make informed decisions about participation. It was important to reassure the recipient that their participation would be completely anonymous to the staff at the Transplant Unit, and that their treatment would not be affected by their decision to participate.

Stamped self-addressed envelopes were provided at both stages of data collection to maximise inclusion. Contact was made with the General Practitioner of recipients who had requested that he/she was made aware of their participation.

Under the arrangements of the honorary contract, the researcher was insured against indemnity. Although this research did not include invasive procedures or drug trials, some questions may have caused distress and may have embarrassed respondents, causing psychological harm (Bell, 1999), therefore it was important to acknowledge the potential for psychological disturbance within the sample. To address this issue, a workplace counsellor was available to all participants. Both stages of data collection reminded the recipient that they could contact the researcher in writing, with any queries, and/or withdraw from the research at any time.

The researcher was aware that some recipients were excluded from participation. Prior to administering any information about the research, advice was sought from the MDT with regards to recipients who should be excluded due to the possibility of experiencing unacceptable levels of distress. The MDT refined the potential participant list based upon consideration of the following questions:

- Has the recipient any severe psychological problems which may indicate adverse emotional effects with regards to their well being, or with regards to providing false and/or inaccurate data?
- Can the recipient be verified as over eighteen years of age?
- Is the patient currently receiving medication for any severe psychological disorder?

The refined inclusion criteria was therefore, any individual of between eighteen, and forty years old at the time of transplantation, who were at least six months post-operative with no known severe psychological problems or medically treated psychological disorders.

3.7. Data Analysis

Once the completed questionnaires were returned, the responses were entered into a score sheet (Derogatis, 1983) (Appendix 11, p.135). The researcher was then able to calculate the t-score and a data set was initiated using the Statistical Package for the Social Sciences (Version 12) to record the scores in numerical form ready for analysis. SPSS was chosen due to the fact that it is the most widely used statistical analysis package in the social science world (Pallant, 2001).

3.7.1. Tests for Normality

When analysing quantitative data, the level of 'normality' determines the use of parametric or non-parametric tests. A normal distribution of scores within the sample allows parametric tests to be performed on the data (Clegg, 1995). Parametric tests are statistically more acceptable for use in data analysis than non-parametric tests, as they are more precise in their measurement (Pallant, 2001). Furthermore, normality within a sample indicates a more true representation of the population from which it was extracted, and thus attains greater credibility of results (Bryman & Cramer, 2005). The following tests were used to establish the normality of PAIS t-scores within the sample:

3.7.2. Histogram

The actual shape of PAIS t-score distribution within the sample can be illustrated in a histogram. A symmetrical bell-shaped curve with the greatest frequency of scores in the middle with smaller frequencies of scores to the extremes indicates normality within a sample (Pallant, 2001).

3.7.3. Kolmogorov-Smirnov

This test was completed to give an actual statistical value which would indicate the normality of the distribution of scores within the sample. In this test, a significance value of greater than 0.05 indicates normality. A significance value of less than 0.05 indicates a violation of the assumption of normality (Bryman & Cramer, 2005).

3.7.4. Q-Q plot

This test was completed to further support the histogram and Kolmogorov-Smirnov test. The plot illustrates the observed value for each score plotted against the expected value

assuming that distribution of PAIS t-scores were normal. A reasonably straight line of observed scores against expected scores indicates normal distribution (Bryman & Cramer, 2005).

3.7.5. Descriptive Statistics

As Clegg (1995) suggests, descriptive statistics are the foundation for analysis of results within a sample, and provide useful information in exploratory research, often revealing emerging trends within data. As a result of this suggestion, frequencies, means and medians were performed on the data collected, in order to obtain an initial understanding of the information provided by the sample, with the aim of addressing the second research question (Chapter 1, p.7), relating to the psychosocial adjustment of cardiopulmonary transplant recipients.

3.7.6. Parametric Tests

Parametric tests were employed to reveal any significance within the demographic data collected from the PAIS-SR and transplant specific questions. Parametric tests may be employed when certain conditions are satisfied. These conditions include:

- Normal distribution of scores
- Acceptable sample size relevant to the population from which the sample was drawn
- Interval or ratio scaling; more than ordinal data
- Means and medians appear to fall within expected limits.

(Bryman & Cramer, 2005)

The following statistical tests were used to address the third research question (Chapter 1, p.7).

3.7.7. Independent Samples t-test

An independent samples t-test is used to compare the mean scores of two different categories of people or conditions (Pallant, 2001). This test was performed on the data collected relating to gender, employment and marital status, due to the nature of the responses being consistent with categorical data.

3.7.8. Levene's test for equality of variances

Within the results of the independent samples t-test, Levene's test for equality of variances is reported. This tests whether the variation of the scores for the two categories is the same, and the outcome of this test determines which t-value is appropriate to use (Bryman & Cramer, 2005). If the significance level of this test is greater than 0.05, then the first line of the table should be referred to. If the significance level is less than 0.05, then the second line of the table should be referred to in accordance with 'equal variances not assumed' (Pallant, 2001).

3.7.9. One-way ANOVA

A one-way ANOVA (analysis of variance) is useful to compare the mean scores of more than two different categories of people or conditions (Pallant, 2001). This test was performed on data collected relating to access to provision and years post transplant, due to the nature of the responses being consistent with more than two categories.

3.7.10. Principle Component factor Analysis

This 'data reduction' technique is a useful tool in determining a number of smaller components which account for the most of the variability within the scores (Pallant, 2001). This technique was used in the context of this research, in an attempt to reveal interesting information, regarding which of the seven domains (if any) within the PAIS-SR, contributed most to the overall score.

Chapter 4 - Results

4.1. Participation and Response Rate

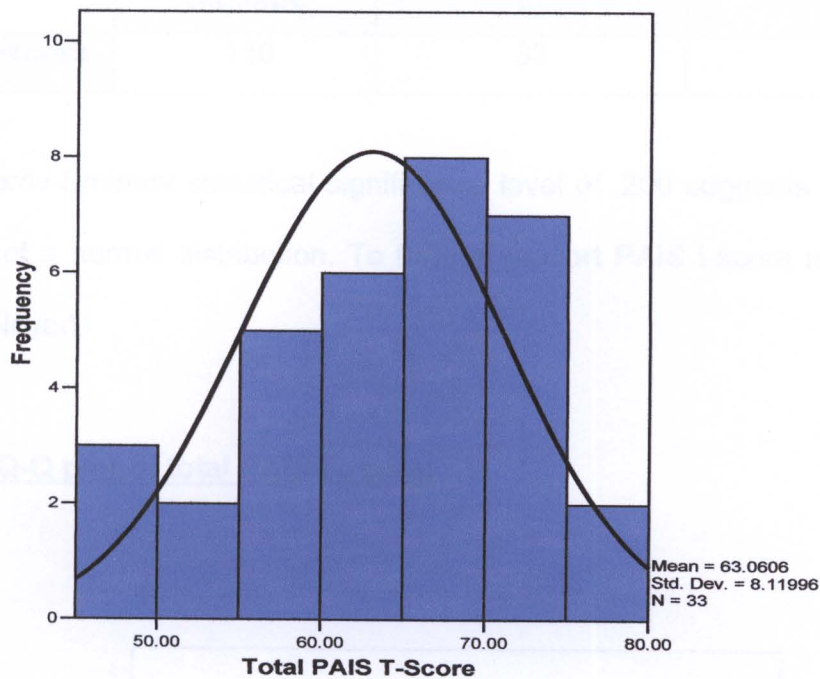
Recipients who participated in the research ranged in age from 20 years old to 54 years old at the present time, with the mean age being 37 years old. There were 22 males and 11 females who participated in the research, comprising of 26 heart transplant recipients, 5 lung transplant recipients and 2 heart/lung transplant recipients.

N=33 consent forms and completed questionnaires were returned. N=3 consent forms were returned stipulating a desire not to participate in the research. N=7 consent forms were received stipulating a desire to participate, but no questionnaire was subsequently received. N=26 consent forms were not returned. This gave an overall, satisfactory completed questionnaire response rate of 47.8%

4.2. Data Analysis

Data collected in this research was entered into the SPSS Version 12, database and was analysed using descriptive statistics, independent t-tests, one-way ANOVA's and principle components analysis. Analysis began with important tests of normality within the PAIS t-scores. Such tests included a histogram, followed by a Kolmogorov-Smirnov test for normality and further supported by a Q-Q plot. Descriptive statistics were then performed, including frequencies, means and medians.

Chart 4.2.1. Histogram illustrating the bell shape of the distribution of PAIS t-scores:



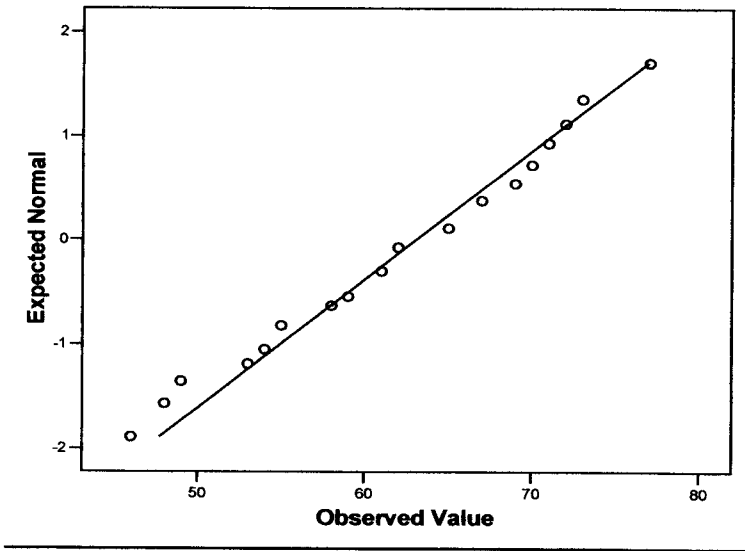
The above histogram suggests that the greatest frequency of PAIS t-scores fall within the bell shaped curve, however there is some potential for skewing (illustrated by the frequencies at this range falling outside of the bell shaped curve) at the PAIS t-score 65-75 range. Therefore, it was decided to perform a Kolmogorov-Smirnov test to discover a statistical level of normality to confirm that the PAIS t-scores were of a normal distribution.

Table 4.2.1. Kolmogorov-Smirnov test for normality within the sample of cardiopulmonary transplant recipients:

	<u>Kolmogorov-Smirnov</u>		
	Statistic	df	Sig.
Total PAIS t-score	.110	33	.200

The Kolmogorov-Smirnov statistical significance level of .200 suggests that the PAIS t-scores were of a normal distribution. To further support PAIS t-score normality, a Q-Q plot was employed.

Chart 4.2.2. Q-Q plot of total PAIS t-score:



The Q-Q plot illustrates the similarity of the observed value for each PAIS t-score plotted against the expected value for each PAIS t-score. There appears to be a

reasonably straight line of observed scores against expected scores, indicating a normal distribution and supporting the histogram and Kolmogorov Smirnov test.

In conclusion, it is suggested that the PAIS t-scores within this sample were of a normal distribution.

4.3. Descriptive Statistics

PAIS scores of less than 60 are from patients who are considered 'well adjusted'.

PAIS scores greater than 60, are from patients who are considered as maladjusted and therefore marginally clinical.

PAIS scores greater than 63, are from patients who are considered as maladjusted, clearly within the clinical range (Derogatis, 1983).

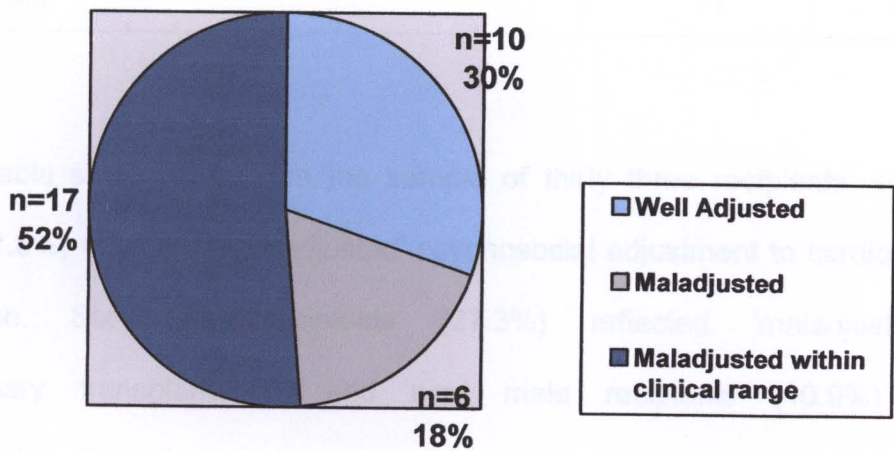
Table 4.3.1. Frequencies and percentages of psychosocial adjustment within the sample of cardiopulmonary transplant recipients:

Psychosocial Adjustment to Illness	Frequency	Percent
Well Adjusted	10	30.3
Maladjusted	6	18.2
Maladjusted within clinical range	17	51.5
Total	33	100

As the above table shows, from the sample of thirty three recipients, ten recipients reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation, six recipients reflected 'maladjustment' and seventeen recipients reflected maladjustment within the clinical range, according to the PAIS-SR scoring system (Derogatis, 1983).

In percentage terms, 30.3% of recipients in this sample reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation and the remaining 69.7% of recipients reflected either 'maladjustment' or 'maladjustment within the clinical range' with the percentages being 18.2% and 51.5% respectively.

Chart 4.3.1. Pie chart illustrating the percentage of psychosocial adjustment status within the whole sample of cardiopulmonary transplant recipients:



The mean psychosocial adjustment to illness score was 63.

The median psychosocial adjustment to illness score was 65.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample reflect 'maladjustment within the clinical range' (Derogatis, 1983).

Table 4.3.2. Frequency and percentage of psychosocial adjustment in relation to gender:

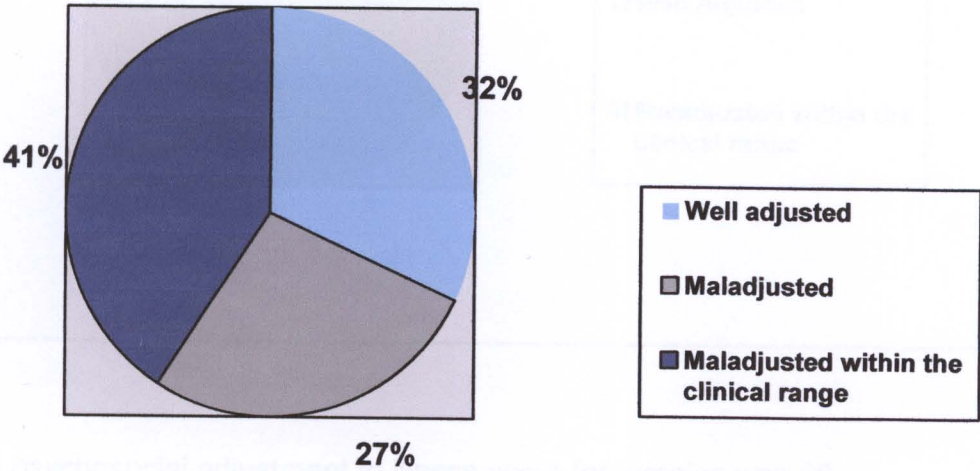
Gender	Psychosocial Adjustment to Illness	Frequency	Percent
Male	Well adjusted	7	31.8
	Maladjusted	6	27.3
	Maladjusted within clinical range	9	40.9
	Total	22	100
Female	Well adjusted	3	27.3
	Maladjusted	0	0
	Maladjusted within clinical range	8	72.7
	Total	11	100

The above table shows, that from the sample of thirty three recipients, seven male recipients (31.8%) reflected ‘well adjusted’ psychosocial adjustment to cardiopulmonary transplantation. Six male recipients (27.3%) reflected ‘maladjustment’ to cardiopulmonary transplantation, and nine male recipients (40.9%) reflected ‘maladjustment within the clinical range’ to cardiopulmonary transplantation. A percentage of 68.2% male recipients reflected ‘maladjustment’ or ‘maladjustment within the clinical range’ in terms of their psychosocial adjustment to cardiopulmonary transplantation.

The above table also shows that from the sample of thirty three recipients, three female recipients (27.3%) reflected ‘well adjusted’ psychosocial adjustment to cardiopulmonary transplantation. No females reflected ‘maladjustment’ to cardiopulmonary

transplantation, and eight female recipients (72.7%) reflected 'maladjustment within the clinical range' to cardiopulmonary transplantation.

Chart 4.3.2. Pie chart illustrating the percentage of psychosocial adjustment status in the male sample of cardiopulmonary transplant recipients:

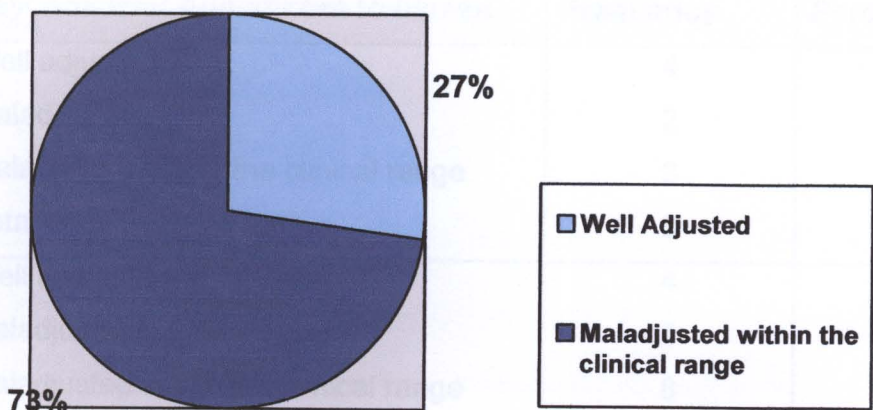


The mean psychosocial adjustment to illness score for males was 62.

The median psychosocial adjustment to illness score for males was 61.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that male cardiopulmonary transplant recipients within this sample reflect 'maladjustment' to cardiopulmonary transplantation. (Derogatis, 1983).

Chart 4.3.3. Pie chart illustrating the percentage of psychosocial adjustment status in the female sample of cardiopulmonary transplant recipients:



The mean psychosocial adjustment to illness score for females was 66.

The median psychosocial adjustment to illness score for females was 67.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggests that female cardiopulmonary transplant recipients within this sample reflect 'maladjustment within the clinical range' (Derogatis, 1983).

It appears that gender has an influence on the level of psychosocial adjustment to transplantation. Females appear to be more likely to fall into the category of 'maladjusted within the clinical range' with higher mean and median PAIS t-scores than males.

Table 4.3.3. Frequency and percentage of psychosocial adjustment in relation to patient access to provision (in miles):

Miles	Psychosocial Adjustment to Illness	Frequency	Percent
0-20	Well adjusted	4	44.4
	Maladjusted	2	22.2
	Maladjusted within the clinical range	3	33.3
	Total	9	100.0
21-49	Well adjusted	4	25.0
	Maladjusted	4	25.0
	Maladjusted within the clinical range	8	50.0
	Total	16	100.0
50-100	Well adjusted	2	25.0
	Maladjusted	0	0
	Maladjusted within the clinical range	6	75.0
	Total	8	100.0

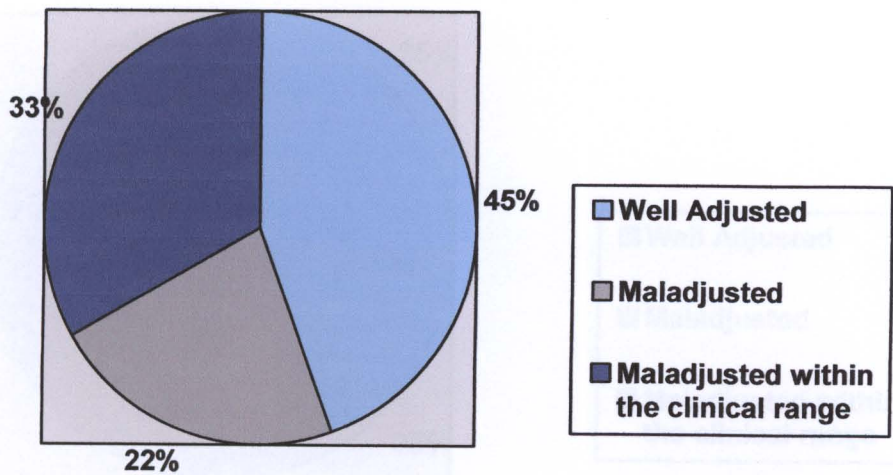
The above table shows that, from the sample of thirty three recipients, there were nine recipients who had access to provision of 0-20 miles. Four recipients (44.4%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Two recipients (22.2%) reflected 'maladjustment' to cardiopulmonary transplantation, and three (33.3%) recipients reflected 'maladjustment within the clinical range'. A total of five recipients (55%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

From the sixteen recipients who had access to provision of 21-49 miles, four recipients (25%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Four recipients (25%) reflected 'maladjustment' to cardiopulmonary transplantation and eight recipients (50%) reflected 'maladjustment within the clinical range'. A total of twelve recipients (75%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

From the eight recipients who had access to provision of 50-100 miles, two recipients (25%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Six recipients (75%) reflected 'maladjustment within the clinical range'.

These results might suggest that in terms of access to provision, the recipients who lived nearer to the transplant unit reflected better psychosocial adjustment to illness than those recipients who lived further away from the transplant unit.

Chart 4.3.4. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who have access to provision of 0-20 miles:

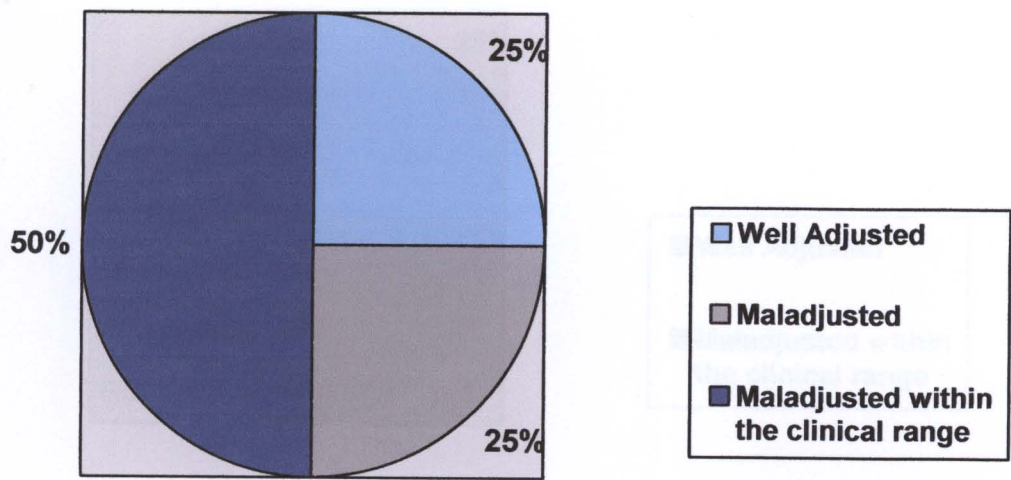


The mean psychosocial adjustment to illness score for access to provision of 0-20 miles was 61.

The median psychosocial adjustment to illness score for access to provision of 0-20 miles was 61.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients who had access to provision of 0-20 miles, reflect 'maladjustment' to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.5. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who have access to provision of 21-49 miles:



The mean psychosocial adjustment to illness score for access to provision of 21-49 miles was 62.

The mean psychosocial adjustment to illness score for access to provision of 21-49 miles was 64.

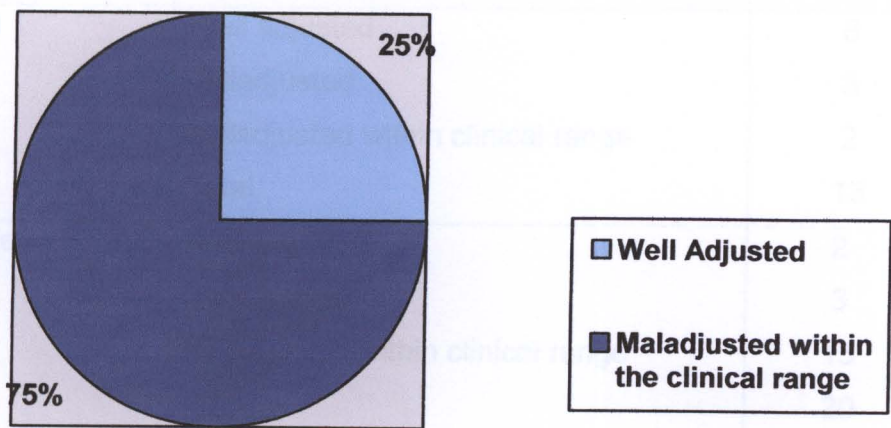
The median psychosocial adjustment to illness score for access to provision of 21-49 miles was 64.

The PAIS-SR suggest that cardiopulmonary transplant recipients who had access to

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients who had access to provision of 21-49 miles, reflect 'maladjustment within the clinical range' (Derogatis, 1983).

know that access to provision appears to be an important factor with regards to psychosocial adjustment to illness. The recipient's mean and median PAIS-SR scores appear to reflect that the distance that they live from the transplant unit

Chart 4.3.6. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who have access to provision of 50-100 miles:



The mean psychosocial adjustment to illness score for access to provision of 50-100 miles was 63.

The median psychosocial adjustment to illness score for access to provision of 50-100 miles was 66.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients who had access to provision of 50-100 miles, reflect 'maladjustment within the clinical range' (Derogatis, 1983).

As acknowledged above, access to provision appears to be an important factor with regards to psychosocial adjustment to illness. The recipient's mean and median PAIS t-scores appear to increase the further distance that they live from the transplant unit.

Table 4.3.4. Frequency and percentage of psychosocial adjustment in relation to employment status:

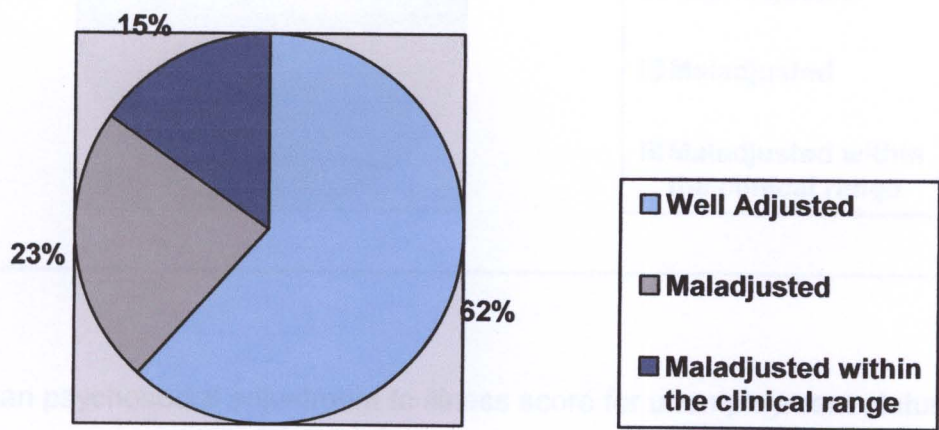
Employment Status	Psychosocial Adjustment to Illness	Frequency	Percent
Employed	Well adjusted	8	61.5
	Maladjusted	3	23.1
	Maladjusted within clinical range	2	15.4
	Total	13	100
Unemployed	Well adjusted	2	10
	Maladjusted	3	15
	Maladjusted within clinical range	15	75
	Total	20	100

The above table shows that, from the sample of thirty three recipients, there were thirteen recipients who were employed, and twenty recipients who were unemployed. From the employed sample, eight recipients (61.5%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Three recipients (23.1%) reflected 'maladjustment' to cardiopulmonary transplantation, and two (15.4%) recipients reflected 'maladjustment within the clinical range'. A total of five recipients (38.5%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

From the unemployed sample, two recipients (10%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Three recipients (15%) reflected 'maladjustment' to cardiopulmonary transplantation, and fifteen (75%) recipients reflected 'maladjustment within the clinical range'. A total of eighteen

recipients (90%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

Chart 4.3.7. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are employed:

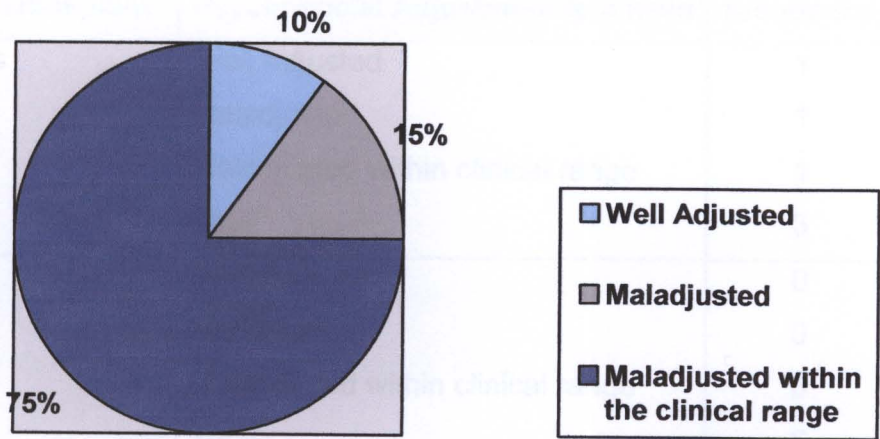


The mean psychosocial adjustment to illness score for employment status was 57.

The median psychosocial adjustment to illness score for employment status was 55.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that employed cardiopulmonary transplant recipients reflect 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.8. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are unemployed:



The mean psychosocial adjustment to illness score for unemployment status was 67.

The median psychosocial adjustment to illness score for unemployment status was 67.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that unemployed cardiopulmonary transplant recipients reflect 'maladjustment within the clinical range' (Derogatis, 1983).

These results strongly suggest that employment is an important factor with regards to psychosocial adjustment to illness within this sample of cardiopulmonary transplant recipients. The data suggests that the likelihood of being 'maladjusted' or 'maladjusted within the clinical range' is much greater if the transplant recipient is unemployed.

Table 4.3.5. Frequency and percentage of psychosocial adjustment in relation to years post-transplant:

Years Post Transplant	Psychosocial Adjustment to Illness	Frequency	Percentage
< 12 months	Well Adjusted	1	33.3
	Maladjusted	1	33.3
	Maladjusted within clinical range	1	33.3
	Total	3	100
1-3 years	Well Adjusted	0	0
	Maladjusted	0	0
	Maladjusted within clinical range	5	100
	Total	5	100
4-6 years	Well Adjusted	1	25
	Maladjusted	0	0
	Maladjusted within clinical range	3	75
	Total	4	100
7-10 years	Well Adjusted	1	20
	Maladjusted	2	40
	Maladjusted within clinical range	2	40
	Total	5	100
> 10 years	Well Adjusted	7	43.8
	Maladjusted	3	18.8
	Maladjusted within clinical range	6	37.5
	Total	16	100

The above table shows that, from the sample of thirty three recipients, there were three recipients who were less than twelve months post-transplant. One recipient (33.3%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. One recipient (33.3%) reflected 'maladjustment' to cardiopulmonary transplantation, and one recipient (33.3%) reflected 'maladjustment within the clinical range'. A total of two

recipients (66.6%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

Table 4.3.5. also demonstrates that, from the sample of thirty three recipients, there were five recipients who were between one and three years post-transplant. All five recipients (100%) reflected 'maladjustment within the clinical range'.

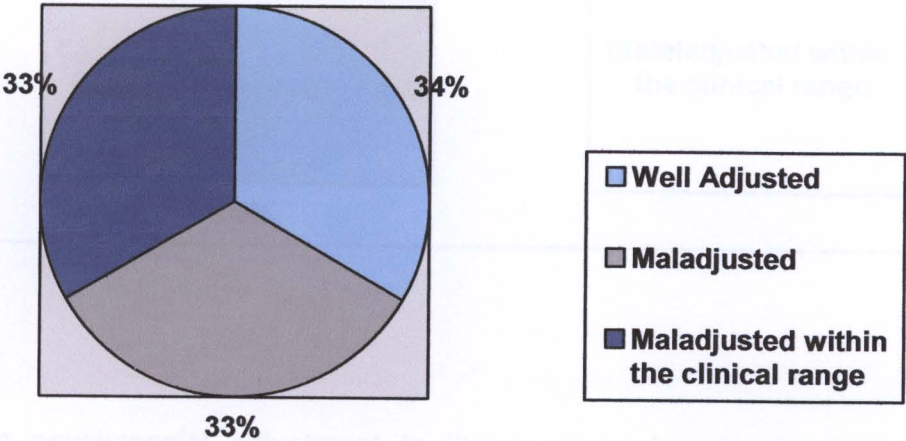
The table indicates that, from the sample of thirty three recipients, there were four recipients who were between four and six years post-transplant. One recipient (25%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Three recipients (75%) reflected 'maladjustment within the clinical range'.

The above table also shows that, from the sample of thirty three recipients, there were five recipients who were between seven and ten years post-transplant. One recipient (20%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Two recipients (40%) reflected 'maladjustment' to cardiopulmonary transplantation, and two recipients (40%) reflected 'maladjustment within the clinical range'. A total of four recipients (80%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

Finally, table 4.3.5. shows that, from the sample of thirty three recipients, there were sixteen recipients who at least ten years post-transplant. Seven recipients (43.8%) reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation. Three recipients (18.8%) reflected 'maladjustment' to cardiopulmonary transplantation, and six recipients (37.5%) reflected 'maladjustment within the clinical range'. A total of

nine recipients (56.3%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

Chart 4.3.9. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are less than twelve months post-transplant:

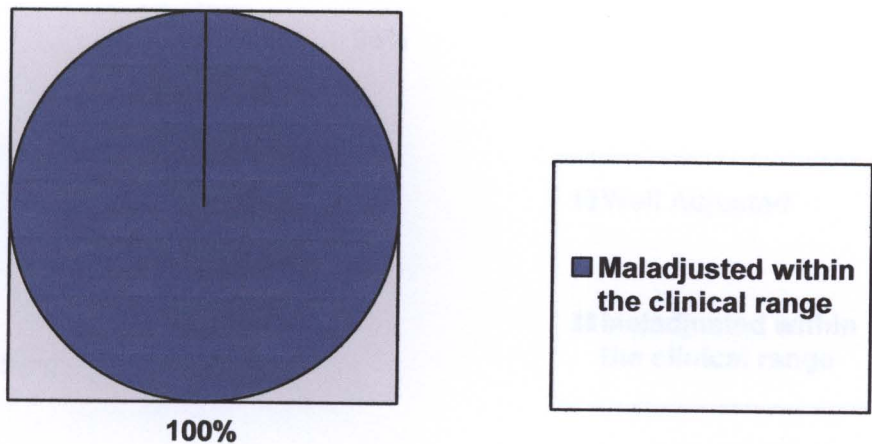


The mean psychosocial adjustment to illness score for less than twelve months post-transplant was 62.

The median psychosocial adjustment to illness score for less than twelve months post-transplant was 61.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample who are less than twelve months post-transplant reflect 'maladjustment' to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.10. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are one to three years post-transplant:

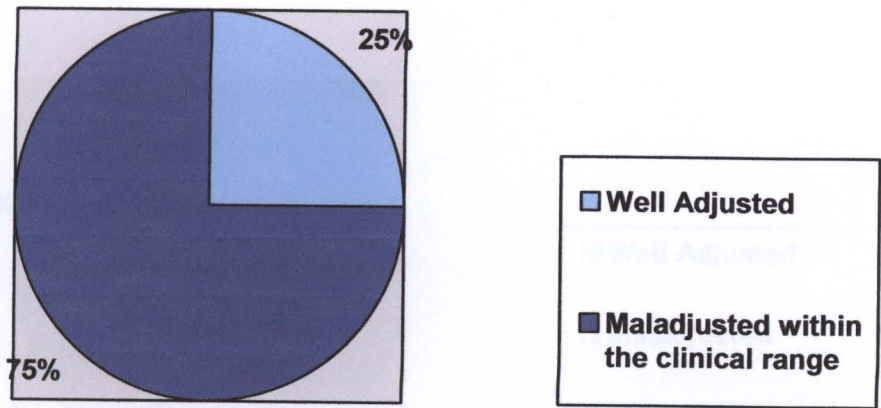


The mean psychosocial adjustment to illness score for one to three years post-transplant was 71.

The median psychosocial adjustment to illness score for one to three years post-transplant was 71.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample who are one to three years post-transplant reflect 'maladjustment within the clinical range' (Derogatis, 1983).

Chart 4.3.11. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are four to six years post-transplant:

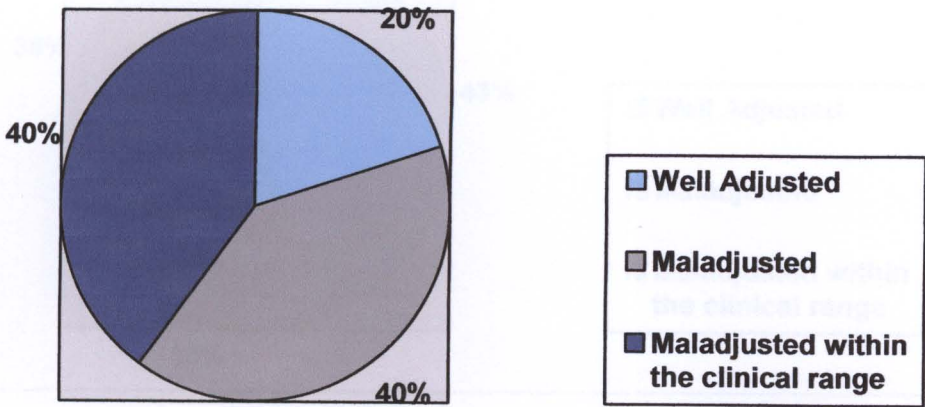


The mean psychosocial adjustment to illness score for four to six years post-transplant was 63.

The median psychosocial adjustment to illness score for four to six years post-transplant was 66.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample who are four to six years post-transplant reflect 'maladjustment within the clinical range' (Derogatis, 1983).

Chart 4.3.12. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are seven to ten years post-transplant:

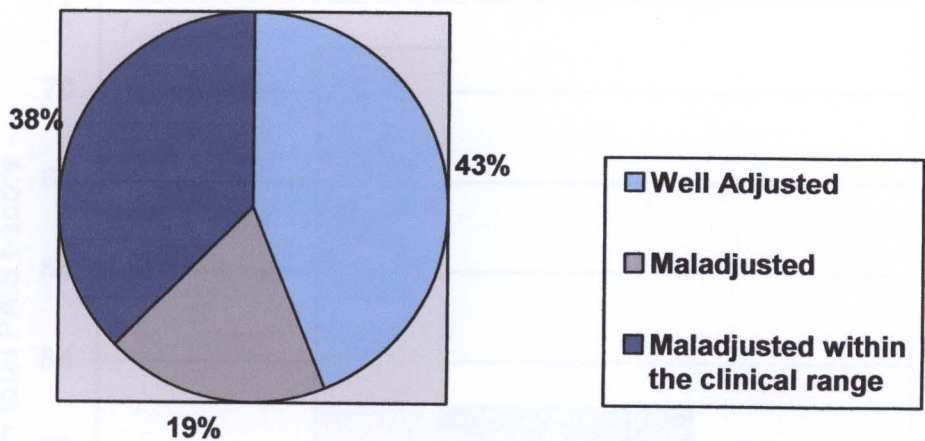


The mean psychosocial adjustment to illness score for seven to ten years post-transplant was 63.

The median psychosocial adjustment to illness score for seven to ten years post-transplant was 61.

In terms of psychosocial adjustment to illness, the mean t-score for the PAIS-SR suggests that cardiopulmonary transplant recipients within this sample who are seven to ten years post-transplant reflect 'maladjustment within the clinical range'. The median t-scores for the PAIS-SR suggests that cardiopulmonary transplant recipients within this sample who are seven to ten years post-transplant reflect 'maladjustment' to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.13. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are more than ten years post-transplant:

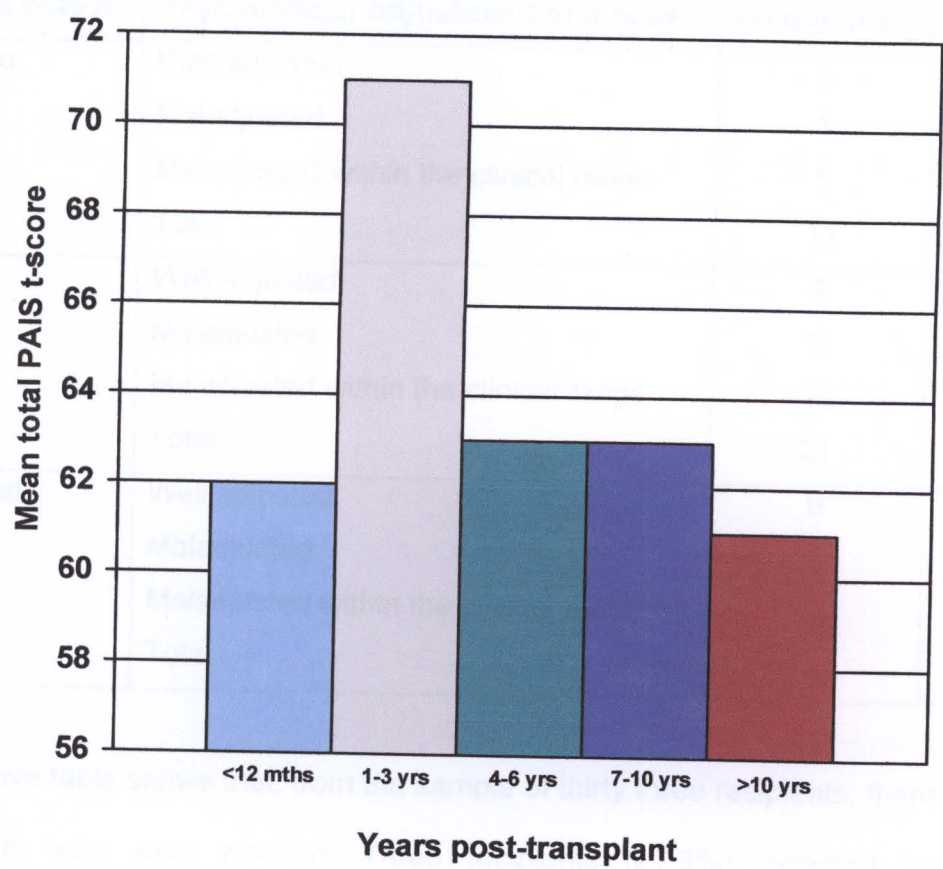


The mean psychosocial adjustment to illness score for more than ten years post-transplant was 61.

The median psychosocial adjustment to illness score for more than ten years post-transplant was 61.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample who are more than ten years post-transplant reflect 'maladjustment' to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.14. Bar graph illustrating overall mean psychosocial adjustment t-score in terms of years post-transplant:



As the above bar chart illustrates, the mean psychosocial adjustment to illness t-score dramatically increases between one and three years post-transplant, suggesting that the most psychosocial difficulty is experienced within this time frame. The lowest mean t-score occurs at greater than ten years post-transplant, suggesting that psychosocial difficulty is reduced, yet still significant, with time.

Table 4.3.6. Frequency and percentage of psychosocial adjustment in terms of marital status:

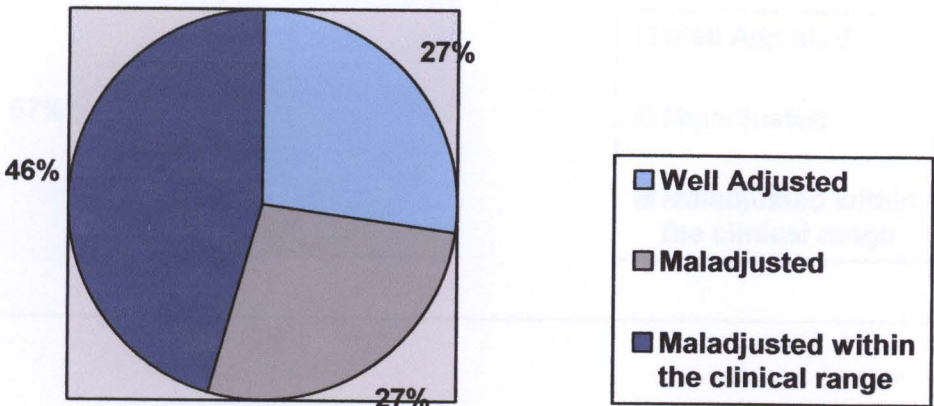
Marital Status	Psychosocial Adjustment to Illness	Frequency	Percentage
Married	Well adjusted	3	27.3
	Maladjusted	3	27.3
	Maladjusted within the clinical range	5	45.4
	Total	11	100.0
Single	Well adjusted	7	33.3
	Maladjusted	2	9.5
	Maladjusted within the clinical range	12	57.1
	Total	21	100.0
Divorced	Well adjusted	0	0
	Maladjusted	1	100
	Maladjusted within the clinical range	0	0
	Total	1	100

The above table shows that, from the sample of thirty three recipients, there were eleven recipients who were married. Three recipients (27.3%) reflected ‘well adjusted’ psychosocial adjustment to cardiopulmonary transplantation. Three recipients (27.3%) reflected ‘maladjustment’ to cardiopulmonary transplantation, and five recipients (45.5%) reflected ‘maladjustment within the clinical range’. A total of eight recipients (72.8%) reflected ‘maladjustment’ to cardiopulmonary transplantation or ‘maladjustment within the clinical range’.

The above table shows that, from the sample of thirty three recipients, there were twenty-one recipients who were single. Seven recipients (33.3%) reflected ‘well adjusted’ psychosocial adjustment to cardiopulmonary transplantation. Two recipients

(9.5%) reflected 'maladjustment' to cardiopulmonary transplantation, and twelve recipients (57.1%) reflected 'maladjustment within the clinical range'. A total of fourteen recipients (66.6%) reflected 'maladjustment' to cardiopulmonary transplantation or 'maladjustment within the clinical range'.

Chart 4.3.15. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are married:

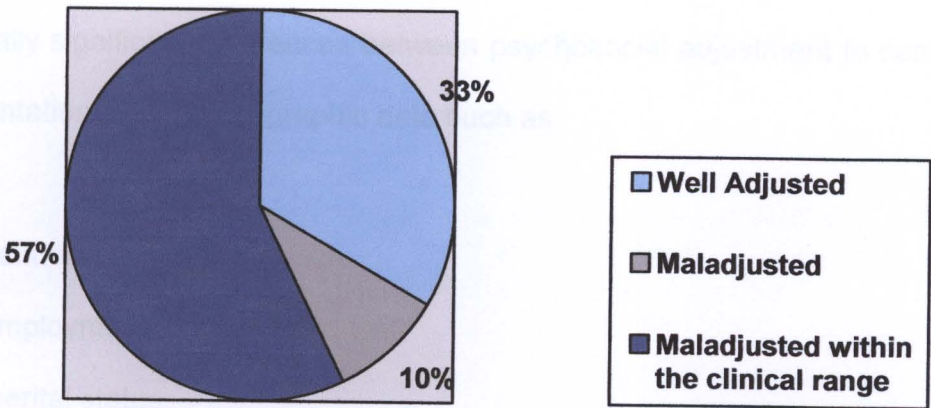


The mean psychosocial adjustment to illness score for married recipients was 64. The median psychosocial adjustment to illness score for more married recipients was 61.

In terms of psychosocial adjustment to illness, the mean t-score for the PAIS-SR suggests that cardiopulmonary transplant recipients within this sample who are married reflect 'maladjustment within the clinical range'. The median t-scores for the PAIS-SR

suggests that cardiopulmonary transplant recipients within this sample who are married reflect 'maladjustment' to cardiopulmonary transplantation (Derogatis, 1983).

Chart 4.3.16. Pie chart illustrating the percentage of psychosocial adjustment status for those recipients who are single:



The mean psychosocial adjustment to illness score for single transplant recipients was 63.

The median psychosocial adjustment to illness score for single transplant recipients was 65.

In terms of psychosocial adjustment to illness, both the mean and median t-scores for the PAIS-SR suggest that cardiopulmonary transplant recipients within this sample who are single reflect 'maladjustment within the clinical range' (Derogatis, 1983).

These results suggest that single recipients are only slightly more likely to fall into the category of 'maladjusted within the clinical range' than married recipients. There are also a larger proportion of married recipients who fall into the category of 'maladjusted' in comparison with single recipients.

4.4. Independent samples t-tests

Three independent samples t-tests were performed to discover if there were any statistically significant differences between psychosocial adjustment to cardiopulmonary transplantation within demographic data such as:

1. gender
2. employment
3. marital status

For all of the independent samples t-tests performed below, Levene's test for equality of variances proved not significant. Therefore, the 2 tailed t-test results for variance not assumed were consulted.

Table 4.4.1. Independent samples t-test of significance between psychosocial adjustment and gender:

	<u>Levene's Test for Equality of Variances</u>		<u>t-test for Equality of Means</u>			
	F	Sig.	t	df	Sig. (2 tailed)	Mean difference
Total PAIS t-score – Equal variances assumed	.095	.760	-1.400	31	.171	-4.13636
Total PAIS t-score – Equal variances not assumed			-1.417	21	.171	-4.13636

The above table illustrates that there is no significant difference in psychosocial adjustment to cardiopulmonary transplantation in terms of gender.

Table 4.4.2. Independent samples t-test of significance between psychosocial adjustment and employment:

	<u>Levene's Test for Equality of Variances</u>		<u>t-test for Equality of Means</u>			
	F	Sig.	t	df	Sig. (2 tailed)	Mean difference
Total PAIS t-score – Equal variances assumed	.991	.327	-4.477	31	.000	-10.25385
Total PAIS t-score – Equal variances not assumed			-4.253	21	.000	-10.25385

The above table illustrates that there is a significant difference in psychosocial adjustment to cardiopulmonary transplantation in terms of employment.

Table 4.4.3. Independent samples t-test of significance between psychosocial adjustment and marital status:

	<u>Levene's Test for Equality of Variances</u>		<u>t-test for Equality of Means</u>			
	F	Sig.	t	df	Sig. (2 tailed)	Mean difference
Total PAIS t-score – Equal variances assumed	.838	.367	.474	30	.639	1.47186
Total PAIS t-score – Equal variances not assumed			.509	25	.615	1.47186

The above table illustrates that there is no significant difference in psychosocial adjustment to cardiopulmonary transplantation in terms of marital status.

4.5. One-way ANOVA's

Two One-way ANOVA's were performed to discover if there were any significant relationships between psychosocial adjustment to cardiopulmonary transplantation within demographic data such as:

- access to provision in miles
- years post-transplant.

Table 4.5.1. One-way ANOVA test of relationship between psychosocial adjustment and patient access to provision:

Total PAIS t-score	df	F	Sig.
Between groups	2	.513	.604
Within groups	30		
Total	32		

The above table illustrates that there is no significant difference in psychosocial adjustment to cardiopulmonary transplantation in terms of access to provision.

Table 4.5.2. One-way ANOVA test of relationship between psychosocial adjustment and years post-transplant:

Total PAIS t-score	df	F	Sig.
Between groups	4	1.373	.268
Within groups	28		
Total	32		

The above table illustrates that there is no significant difference in psychosocial adjustment to cardiopulmonary transplantation in terms of years post transplant.

4.6. Principal Component Factor Analysis

In consideration of all responses by all recipients in this sample, a principal component factor analysis was performed, in an attempt to discover which (if any) of the seven domains within the PAIS-SR, contributed most to the overall score. This factor analysis

yielded three outstanding domains, which are outlined as 'components' in the table below.

Table 4.6.1. Component Matrix indicating the three principle contributing domains to the total PAIS t-score:

PAIS –SR Domain	Component 1	Component 2	Component 3
Health Care Orientation	.238	.666	.324
Vocational Environment	.651	.334	-.327
Domestic Environment	.762	-.272	.236
Sexual Relationships	.501	-.597	.284
Extended Family Relationships	.492	-.141	.257
Social Environment	.537	.429	-.512
Psychological Distress	-.054	.548	.698

The above component matrix indicates that the following domains of the PAIS-SR (in order of importance) are contributing the most to the total PAIS t-score in this sample of cardiopulmonary transplant recipients:

- 1. Domestic Environment
- 2. Health Care Orientation
- 3. Psychological Distress

These results might suggest that domestic environment, health care orientation and psychological distress are major contributing factors to the level of psychosocial adjustment experienced by recipients.

Table 4.6.2. Chart to illustrate variance and percentage of component (domain) contribution:

Component	<u>Total Eigenvalue</u>		
	Total	% Variance	Cumulative %
1	1.845	26.361	26.361
2	1.491	21.299	47.660
3	1.164	16.627	64.287
4	.937	13.381	77.667
5	.716	10.234	87.902
6	.462	6.605	94.507
7	.385	5.493	100

The above table illustrates that component 1 (domestic environment) contributed to the total PAIS score by 26%, component 2 (heath care orientation) contributed 21% and component 3 (psychological distress) contributed 17% of the information related to the total PAIS score.

The above table also illustrates that the three principle contributing domains of domestic environment, health care orientation and psychological distress together, contribute 64% of the information related to the total PAIS score.

Chapter 5 - Discussion and Recommendations

This chapter will discuss significant findings in relation to the research questions posed for this study, and in relation to previous research. The implications for current service provision and suggestions for improvement will be discussed, along with recommendations for future research. Finally, research limitations will be discussed.

5.1. Nationwide Provision of Psychosocial Support in Cardiopulmonary Transplant Units

The first research question had the objective of exploring transplantation, and evaluating the importance of psychosocial input within the current transplant care framework in meeting psychosocial needs of transplant recipients.

- Based upon the literature, to what extent have transplant recipients nationwide been supported through a multi-disciplinary framework of care which addresses psychosocial issues?

It is evident from the literature and previous research (Chapter2, p.9) that cardiopulmonary transplant recipients have psychosocial difficulties and maladjustment problems following their transplant. The current DH stipulations regarding the composition of the MDT (Chapter 2, p.23), for cardiopulmonary transplant recipients, do not provide adequate psychosocial support services to prevent, or manage psychosocial difficulties. The Department of Health acknowledge the impact of psychological and social factors upon transplantation, and are striving for a 'patient-centred' health care

system (DH, 2003b; DH, 2004b). However, a mandatory, comprehensive, uniform, biopsychosocial framework of care for cardiopulmonary transplant recipients has not been provided, nearly six years on from the publication of the National Heart and Lungs Transplant Standards (DH, 2002). This is evident from the anecdotal evidence from the six cardiopulmonary transplant units within the United Kingdom, who report that their psychosocial support is, at best, limited (Chapter 2, p.25). As Dew et al. (2000) suggest, perhaps this situation is as a result of a negative attitude to the importance of psychosocial treatment within medicine. Furthermore, it is suggested that the resources available to cardiopulmonary transplantation are allocated with a biomedical bias rather than a balanced approach to service provision. As mentioned within Chapter 2 (p.24), paediatric cardiopulmonary transplant recipients are provided with extra psychosocial services in the form of child psychologists and child psychiatrists. In the future, the researcher would like to explore the reasons for the differences in service provision between paediatric and adult MDT's as prescribed by the DH (2002).

5.2. Psychosocial Adjustment within the Sample Group

The objective was to explore psychosocial adjustment to cardiopulmonary transplantation, and evaluate the importance of psychosocial input within the transplant care framework in meeting the needs of recipients. In an attempt to address this objective, the researcher asked the following question:

- What is the psychosocial adjustment to cardiopulmonary transplantation, among a sample of recipients aged eighteen to forty at the time of their transplant?

As illustrated in Table 4.3.1. (Chapter 4, p.47), descriptive statistics revealed that 69.7% of the recipients in this sample reflected either 'maladjustment' or 'maladjustment within the clinical range' to cardiopulmonary transplantation. This result supports previous literature, and illustrates the inadequacy of services targeting the psychosocial component of post-transplant survival provided by the transplant MDT. Furthermore, it suggests failure to implement the biopsychosocial patient-centred approach to healthcare, as outlined within the 'NHS Improvement Plan' (DH, 2004b).

White, (2005) suggested that modern medicine neglects psychological and social factors in the treatment of the individual, and the researcher is compelled to support this assertion with regards to the framework of care outlined by the DH (2002) for cardiopulmonary transplant recipients. Smeritschnig et al. (2005) argue that it cannot be proved that all psychosocial difficulties are directly attributable to cardiopulmonary transplantation. Although the lack of pre-transplant data is a limitation of this study, the current research partially supports Stukas et al. (1999), who revealed that 58% of recipients experience pronounced psychiatric distress, and/or diagnosable psychiatric disorders, following their transplant. The study conducted by Stukas et al. (1999), although similar to the present research, cannot be directly compared due to the fact that they investigated psychiatric disturbance within transplantation, which the current research does not. This may account for the higher percentage of recipients reflecting general psychosocial maladjustment within the present research. Finally, the findings of this research support the theory proposed by Napolitano et al. (2002) that the current biomedical approach to cardiopulmonary transplantation is unsatisfactory for recipients and their families, as the outdated biomedical approach does not meet psychosocial need.

5.2.1. Component Factor Analysis

In consideration of all responses from all recipients, the researcher decided to explore the possibility of any outstanding domains within the PAIS, which were contributing most, to the total score. As Table 4.6.1. (Chapter 4, p.75) illustrates, a component factor analysis yielded three major contributing domains. Each outstanding domain is outlined in order of percentage contribution below, and is discussed in relation to previous research.

Domain One: Domestic Environment

This domain contributed 26% to the total PAIS score, which indicates that domestic environment is an important risk factor when considering psychosocial adjustment to cardiopulmonary transplantation. With reference to the purpose of this domain within the PAIS (Chapter 3, p.33), this result suggests that recipients' experience increased difficulties with adaptation to domestic and family roles and relationships, post-transplant.

This finding supports research by Bunzel et al. (1999) into role adaptation difficulties, and research by DeMaso et al. (2004), who conclude that family functioning is an influential determinant of the emotional adaptation of cardiopulmonary transplant recipients. Therefore, the results of this research imply the need for psychosocial intervention such as family liaison and counselling therapy, which may provide mediums by which families can learn effective communication and coping skills to enhance their relationships and the post-transplant experience. Such intervention should be considered a budget priority for the DH, NSCAG and individual transplant MDT's within their transplant care framework.

Domain Two: Health Care Orientation

This domain contributed 21% to the total PAIS score, which indicates that health care orientation is another important risk factor when considering psychosocial adjustment to cardiopulmonary transplantation. With reference to the purpose of this domain within the PAIS (Chapter 3, p.33), this result suggests that transplant recipients' health care beliefs, relationships with health care professionals, and mistrust of treatment contribute to maladjustment to cardiopulmonary transplantation.

This result indicates a failure to meet the key aim of a 'patient centred' NHS (DH, 2004b), because poor health care orientation implies that cardiopulmonary transplant patients are not receiving a balanced biopsychosocial approach, which is considered vital to a 'patient-centred' NHS (DH, 2004b). This finding supports Hart (1997) who suggests that the doctor-patient relationship leaves individuals feeling frustrated at being treated within a predominantly biomedical approach, where their wider social environment and spiritual welfare are disregarded. It may be suggested that a less hierarchical attitude change within the institute of medicine might serve to facilitate improved relationships with patients who have long-term chronic illness, such as transplant recipients. However, psychosocial intervention such as patient education and social rehabilitation might serve to encourage more autonomy and inspire more confidence for the recipient, in order to fulfil the aim of the DH (2004b), where patients become integral members of the health care team, in relation to their treatment. Therefore, the recruitment of healthcare professionals who might facilitate an improvement in health care beliefs, and an improvement in psychosocial adjustment should become a cardiopulmonary transplant service budget priority for the DH, NSCAG and individual transplant MDT's.

Domain Three: Psychological Distress

This domain contributed 17% to the total PAIS score, which indicates that psychological distress is another important risk factor when considering psychosocial adjustment to cardiopulmonary transplantation. With reference to the purpose of this domain within the PAIS (Chapter 3, p.35), it appears that recipients experience increased difficulties with some major indicators of psychological distress such as depression, hostility, anxiety, reduced self-esteem and body image, post-transplant.

It is acknowledged that the major indicators of psychological distress, according to Derogatis (1983), are wide ranging and could have different implications. However, this result supports previous research and suggestion that transplantation exposes the recipient and their family to innumerable, repeated psychological traumas (Serrano-Ikkos et al., 1999; Stukas, et al., 1999; Baines & Jindal 2002; DH, 2003b). This risk factor requires serious consideration and it is suggested that the need for long-term recruitment of mental health professionals, who are specialists in conditions such as cardiopulmonary transplantation, should become a budget priority for the DH. and NSCAG in order to fulfil their aims. Individual transplant MDT's must also apply for, and allocate, resources to facilitate improved psychological adjustment for their recipients. It is suggested that specialist mental health professionals should become an intrinsic part of the transplant MDT.

5.3. Demographic Factors Influencing Psychosocial Adjustment

Along with general demographic information obtained within the PAIS-SR, the researcher gained some transplant specific information with each questionnaire. The objective was to explore the possibility of any relationship in terms of psychosocial

adjustment to cardiopulmonary transplantation within demographic details, and to gain an insight into what influences psychosocial adjustment to cardiopulmonary transplantation.

5.3.1. Employment

Descriptive statistics within Table 4.3.4. (Chapter 4, p.57) illustrate that employment status is a major risk factor for psychosocial maladjustment within this sample. It is worth presenting the percentages again here, as they are enlightening. 61.5% of employed recipients reflected 'well adjusted' psychosocial adjustment to cardiopulmonary transplantation, whilst 90% of unemployed transplant recipients reflected 'maladjustment' or 'maladjustment within the clinical range'. Furthermore, although this sample was limited in size, an independent samples t-test revealed that there was a statistically significant difference between employed and unemployed transplant recipients in terms of psychosocial adjustment to cardiopulmonary transplantation.

It is acknowledged that barriers to the attainment of paid employment include physical, medical and emotional difficulties (Cicutto et al., 2004; Dew et al., 2002). Furthermore, active financial discouragements, in terms of the complexities of state benefits, hinder the attainment of paid employment (Dewson, Davis & Loukas, 2004). However, these findings firmly support previous research and theory by Winsett (1998) and Reyes et al. (2004) who suggested that transplant recipients should be encouraged to return to work if at all possible, as they show better adjustment to transplantation and experience less fatigue if they are employed. Currently, the social worker within the MDT may advise recipients with regards to employment and benefits. However, it is suggested that greater assistance from the transplant MDT in terms of liaison and collaboration, may

aid recipients and potential employers in accepting and understanding the complex needs of patients and unique transplant situation. Furthermore, perhaps as part of a Government Strategy, the unique situation and requirements of transplant recipients may be considered with reference to employment and the state benefit system. To this end, it is suggested that the transplant MDT consider the recruitment of a job placement co-ordinator, who could assess recipients' circumstances and attempt to provide suitable employment roles (particularly for younger recipients), in order to facilitate a shift away from the sick role, and potentially enable healthy psychosocial adjustment to the transplant experience.

5.3.2. Access to Provision

Descriptive statistics within Table 4.3.3. (Chapter 4, p.52) support the theory proposed by the researcher, that recipients' encounter greater psychosocial difficulties when they have less access (in terms of distance) to transplant specific service provision. Descriptive statistics reveal increased levels of psychosocial 'maladjustment' relative to an increased distance lived from the transplant unit. However, in a climate of improved public service provision and travel cost re-imbursement for those who have low income, there does not appear to be any clear explanation for these findings.

Nevertheless, this result supports the theory by Dew et al. (2004) which suggests that psychosocial difficulties may be difficult for the transplant team to manage satisfactorily due to the wide geographical dispersion of recipients, and also illustrates the challenge in achieving one of NSCAG's key aims which states that "it is important to ensure that patients remote from the treatment centres are not served less well..." (DH, 2005, p.5). As Carlson and Bultz (2003) argue, psychosocial distress can only be treated by

qualified, knowledgeable health professionals with experience of psychosocial care within certain chronic illness groups. Current transplant specific provision does not include local outreach services for transplant recipients in their communities which may facilitate improved psychosocial adjustment. However, healthcare professionals who are trained and knowledgeable of the issues surrounding transplantation are difficult to recruit (DH, 2004a), and it is suggested that this lack of specialist services serves to compound the problem. Statistical significance was not found between psychosocial adjustment and access to provision. This might be explained by limited sample size and further reduction of recipients within each distance category.

5.3.3. Years Post Transplant

As illustrated in Table 4.3.5. (Chapter 4, p.60), and Chart 4.3.14. (Chapter 4, p.67), the most severe psychosocial maladjustment occurs between one and three years post-transplant, where 100% of the recipients reflected 'maladjustment within the clinical range'. This strongly supports previous research by Dew et al. (2000) who found that anxiety disorders have their onsets largely during the first years after the transplant, with 25% of recipients experiencing MDD during the first three years after their transplant. This result also supports Stukas et al. (1999) who report that PTSD has been found in heart transplant recipients, indicating a failure to adjust to the experience. Furthermore, research by Salyer et al. (2003) which suggested that psychosocial adjustment, although imperfect, is better amongst the longest survivors, has to be contradicted in this instance, because although there was a marked increase in psychosocial maladjustment among recipients who were one to three years post-transplant, there remained a significant percentage of recipients within all of the categories of time post-transplant

who reflected 'maladjustment' or 'maladjustment within the clinical range' to cardiopulmonary transplantation.

5.4. Implications for Current Service Provision

The question follows as to how the preceding results might translate into staffing needs for psychosocial health professionals involved in the MDT transplant programme, when the results of this research suggest that services provided for cardiopulmonary organ transplant recipients are inadequate. Firstly, the findings should remind transplant health care professionals, of NSCAG Clinical Governance guidelines, which encourage the routine consideration of the holistic needs of recipients, and encourage researchers attached to the MDT to actually carry out investigations of patient experiences.

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Secondly, as Schein et al. (2003) illustrate, it is imperative that staff members respect each other's influence and contribution to the MDT, regardless of their own theoretical orientation or belief system. They must also refrain from judging patients or dismissing coping strategies, and must aspire to provide adequate support services in order to meet their aim, of maximising the quality of life of all transplant recipients and their families. According to Skotzko et al. (2001) each transplant centre should review its psychosocial staffing and services to discover if these are adequate. It is therefore suggested that all members of the transplant MDT consider the following questions:

- Do members of the MDT feel they have adequate training, skills and devotion of time to provide information, advice, counselling and support, to all recipients and their families as the DH suggests they should?

- Is the MDT able to provide assessment and referrals for all aspects of psychosocial treatment for each recipient? If so, how long is the waiting time for consultation with this particular specialist?
- Are there any mechanisms in place whereby the recipient may seek emergency help if their psychosocial condition deteriorates whilst on the waiting list for clinical intervention?

5.5. Suggestions for Improvement to Current Service Provision

The following suggestions are outlined with a view to facilitating enhanced standards for cardiopulmonary transplant recipients, and should be viewed as topics for consideration within the MDT.

- Expansion of the MDT could, at least, include a Clinical Psychologist, who may provide individual and group interventions, and an employment co-ordinator who could be specifically appointed to help recipients with all aspects of employment.
- Improvement of support groups in terms of accessibility might include telephone and internet based services, along with 1-on-1 mentoring programmes with other like-minded recipients.
- Consideration of a National Service Framework, specific to transplantation, which would provide uniformity and a structured framework of care for all involved in the cardiopulmonary transplant process.
- DH and NSCAG budget increases to enable the implementation of the biopsychosocial approach to cardiopulmonary transplantation within MDT improvements.

Finally, it is suggested that the development of procedures to standardise psychosocial intervention within the MDT, and self-assessment of services provided to transplant recipients, is required to make data comparable across transplant units.

5.6. Clinical Significance versus Statistical Significance

Descriptive statistics in the form of frequencies, means and medians facilitated the production of useful, visual information about the clinical significance of the results of this study. Clinical significance has been described as a conclusion about whether or not an observation has any practical meaning to patients and health care providers (Huck, 2000). To illustrate this point, in a medical research trial, a type of treatment might be found to have a statistically significant effect on a group of patients, but the effect might not have any practical importance (clinical significance). According to Huck (2000), descriptive statistics often reflect the critically important distinction between statistical significance and clinical significance and many studies containing statistically significant results are trivial in terms of clinical significance.

In essence, although results within this research revealed that employment was the only statistically significant contributing factor to psychosocial adjustment, it may be argued that the descriptive statistics within this research are clinically significant, due to the fact that they highlight risk factors for psychosocial maladjustment that careful management and consideration may be able to mitigate against.

5.7. Recommendations for Future Research

After a review of the literature, particularly results from American studies, the researcher believes that cardiopulmonary transplant recipients in the United Kingdom do have the

capacity for healthy psychosocial functioning after transplantation. However, more research is needed due to the paucity of long-term or longitudinal follow-up studies of cardiopulmonary transplant recipients. As DeMaso et al. (2004) suggest, factors that may facilitate or hinder adjustment after cardiopulmonary transplantation have not been well defined, and require much further research to establish any causal variables. Furthermore, the researcher believes that the scope for designing a 'transplant specific' psychosocial adjustment questionnaire is enormous.

Future research from stratified sampling may consider the development of risk factor models to examine varying patterns of psychosocial functioning over time and within social environment in order to consider and implement strategies which may enhance psychosocial adjustment in these patients. However, the following suggestions for future research should be considered.

- As the National Heart and Lung Standards (2003) suggests, a dedicated team of workers, separate from the transplant team management, should collect data with specific relevance to quality of life within cardiopulmonary transplant recipients.
- Patient and family views should increasingly be sought in order to provide a 'patient-centred' service which meets their needs.
- Longitudinal research would be beneficial in terms of investigating whether poor psychosocial adjustment is directly attributable to cardiopulmonary transplantation.
- Independently funded multi-centre, qualitative and quantitative research may enhance the current research, and reveal increased numbers of individuals who

might benefit from psychosocial service provision, and is needed as a further assessment of needs.

- Increased survival may necessitate investigation into the impact of transition between paediatric and adult cardiopulmonary units, upon psychosocial adjustment, with specific relevance to the composition of the cardiopulmonary transplant MDT.
- Research into the feasibility of the expansion of the MDT via the establishment of local outreach centres, with specialist psychosocial healthcare professionals, who have specific knowledge of transplantation, to serve recipients within their communities.
- Research into increased use of telephone and internet based communication and education services within the UK, with a view to addressing the geographical dispersion of recipients.
- Audits of patient expectation, satisfaction and suggestion for improvement should be implemented routinely.

5.8. Limitations of the Research

As Smeritschnig et al. (2005) suggested, it cannot be proven whether the psychosocial maladjustment experienced by participants is directly attributed to the transplant experience, and this is a limitation of the current research. Sample size was another limitation of this research, and therefore the results need to be approached with some caution. Further research in the form of a multi-centre study would be advantageous to transplantation programmes within the UK in order to gain a more adequate, comprehensive representation of the psychosocial adjustment status of all of its

recipients. However, due to the specialist nature of cardiopulmonary transplantation and the fact that NSCAG commission services with a low case load, it is argued that, although the sample size was limited, the clinical significance of the findings may be high. The number of identified potential participants for this research was 69, and from this population, 33 recipients participated. Therefore the results of this study apply to 49% of the potential population at the transplant unit where the research took place.

It may also be argued that those suffering from maladjustment to cardiopulmonary transplantation are more likely to participate in research of this nature, as they may feel that they will receive more support by highlighting their feelings.

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The researcher felt that being unable to obtain transplant specific qualitative data, which would enrich and enliven this research by providing in-depth information from the patient perspective, was a limitation. However, this was a limitation which was out of the control of the researcher due to strict LREC stipulation.

Chapter 6 - Conclusion

With reference to the first research question posed for this study, it has been concluded that despite improved survival rate post-transplant, the long-term emotional functioning of recipients is unclear (DeMaso et al., 2004). Recipients experience chronic physical illnesses, require life-long immunosuppression therapy, and endure the continued threat of rejection of the transplanted organ. Therefore, understanding the adaptation and coping of these patients to such a stressful life experience may have important implications for long-term graft and recipient survival. It is apparent to most people that a pathological disease or chronic illness can have an effect on a person's mind therefore it is not surprising that organ transplant recipients, who have had to endure all of the associated interventions, may develop depression and/or anxiety.

With reference to the two further research questions posed for this study (Chapter1, p.7), it was identified that 69.7% of the cardiopulmonary transplant recipients sampled, reflected 'maladjustment' or 'maladjustment within the clinical range' to cardiopulmonary transplantation. This research has also identified groups of patients at higher risk for adjustment problems following their transplant, namely, those who are unemployed, those who live further away from the transplant unit, and those who are between one and three years post-transplant.

The most compelling argument for incorporating a solid psychosocial component into all cardiopulmonary transplant MDTs is the clinically significant number of patients who might benefit from such a change. The integration of psychosocial care into on-going

medical and post-transplant care can offer critical opportunities for the early intervention, and development of strategies for transplant recipients and their families, before the development of more severe emotional adjustment difficulties or medical adherence problems are experienced.

As Carlson and Bultz (2003) acknowledge, psychosocial distress can only be treated by qualified, knowledgeable health professionals with experience of psychosocial care within certain chronic illness groups. It is suggested that such health professionals involved within the transplant MDT, working towards a common goal, should include social workers, dieticians, specialist transplant nurses, employment placement coordinators, psychologists and psychiatrists. However, the acknowledgement of the comprehensive, imperative roles of such MDT health professionals within the DH National Heart and Lung Transplant Standards has yet to be translated into a comprehensive, mandatory psychosocial rehabilitative framework of care. Such acknowledgement might be reflected in future budgeting and planning within the DH, and therefore may become a fundamentally important aspect of consideration within the NSCAG budget for cardiopulmonary transplantation. To this end, it is suggested that NSCAG and the DH, within its National Heart and Lung Transplant Standards, clearly outline the obvious need for increased mandatory roles within the transplant MDT as an overall improvement to the quality of care that recipients can expect from their transplant units.

The transplant care framework has been of immeasurable value, but the biomedical approach to healthcare was established before psychological and social sciences had adequately developed. Therefore, it is suggested the transplant care framework should

now be expanded to include psychological and social factors if it is to realise its full potential. As Schein et al. (2003) suggested, health care can be enhanced by recognising the addition of psychosocial factors to the customary biological ones. A comprehensive, holistic framework of care may encourage improvements in morbidity and mortality among transplant recipients and may potentially enhance the post-transplant experience of recipients who are coping with their condition, but (who) could cope even better with additional carefully structured interventions from appropriate members of the MDT within the transplant programme.

Clearly, the time has arrived for transplant recipients to expect a holistic biopsychosocial model of health within their transplant programmes. All members of the transplant MDT must acknowledge the importance of treating transplant recipients' physical, social and emotional needs, and must prioritise the provision of such services within their budget, as a vital part of their transplant care framework. Furthermore, increasing support is needed from the Government and the DH, in order to prioritise recruitment of mental health professionals who have, or are prepared to attain, expertise about the medical and psychosocial aspects of specialist conditions such as transplantation, and how to work with recipients in order to facilitate an improved post-transplant experience and overall quality of life than the one currently being experienced by recipients.

It is suggested that psychosocial interventions are likely to result in physical benefits for the patient as well as lowering costs for treating disease. Medical tests, prescriptions and surgical interventions obviously play a role in post-transplant management, but only a partial one (Schein et al., 2003). The goal is to enhance the capacity of patients to

move beyond disease and illness, to find a way of life that fulfils their potential for living as psychosocially healthy, socially connected, spiritually fulfilled people.

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Appendix 1

Questions originally intended for transplant specific data collection.

1) Are you?

Male _____ Female _____

2) Are you?

Employed _____ In Education _____ Retired _____ Unemployed _____ Other _____

Please give any further details:

3) How far do you live from the hospital?

0-20miles _____ 21-49 miles _____ 50-100 miles _____ over100 miles _____

4) How long has it been since your transplant?

6-12 months ____ 1-3years ____ 3-5years ____ 5-10years ____ over 10years ____

5) How many different prescription medications do you take?

1-5 ____ 6-10 ____ 11-15 ____ more than 16 ____

6) How often do you attend the transplant out-patients clinic?

Weekly ____ Fortnightly ____ Monthly ____ Less often ____

7) Do you have any other health problems?

Yes ____ No ____

Please give any further details:

8) How satisfied are you with what you know about your health?

_____	_____	_____	_____
_____	_____	_____	_____
Completely Dissatisfied	Dissatisfied	Satisfied	Completely Dissatisfied

9) Do you take ALL of your prescribed medication?

Yes	_____	No	_____
	_____		_____

10) If not, why not? Please give any details:

11) Have you been diagnosed with depression since your transplant?

Yes	_____	No	_____
	_____		_____

12) How was, or how is this treated? Please give details:

13) Did you, or do you feel that your treatment was adequate?

Yes	_____	No	_____
	_____		_____

Please give any details or reasons:

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

THANK YOU

Appendix 2

The SF-36 V2 Questionnaire.

Appendix 3

The PAIS-SR Questionnaire.



Appendix 4

Questions used for transplant specific data collection.

South Manchester University Hospitals 
NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT
Tel: 0161 998 7070

Additional Questions

1) How far do you live from the hospital?

0-20miles

☐

21-49 miles

☐

50-100 miles

☐

over 100 miles

☐

2) How long has it been since your transplant?

Less than 12 months

☐

1-3 years

☐

4-6 years

☐

7-10 years

☐

over 10 years

☐

THANK YOU



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 5

LREC approval letter

SL14 Favourable opinion following consideration of further information
Version 2, October 2004



Tameside & Glossop Local Research Ethics Committee

Room 181
Gateway House
Piccadilly South
Manchester
M60 7LP
0161 237 2336
carol.ebenezer@gmscha.nhs.uk

31 March 2005

Miss Hilary Cheater

Dear Miss Cheater

Full title of study: *An exploration of psychosocial adjustment to cardiopulmonary transplantation*
REC reference number: 05/Q1402/6
Protocol number:

Thank you for your letter of 17 March 2005, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The favourable opinion applies to the research sites listed on the attached form.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type:	Version:	Dated:	Date Received:
Application	3	21/01/2005	24/01/2005
Application	part pagea0 and 16	25/02/2005	25/02/2005
Investigator CV		21/01/2005	24/01/2005
Investigator CV	Supervisor CV x2	21/01/2005	24/01/2005
Protocol	2	21/01/2005	24/01/2005

An advisory committee to Greater Manchester Strategic Health Authority

Appendix 6

Research covering letter.

South Manchester University Hospitals 
NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT

Tel: 0161 998 7070

Dear

I am a post-graduate MSc student in Health Promotion, doing a project looking at how young people aged between 18 and 40 years old at the time of their transplant, cope with some quality of life issues after heart or lung transplant. I am writing to you, to invite you to take part.

Enclosed, is an information leaflet and a consent form. If you wish to take part, you only have to fill in the consent form and return it to me at the Transplant Unit, in the stamped self-addressed envelope provided.

Yours Sincerely,

HILARY CHEATER



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 7

Patient Information Sheet.

South Manchester University Hospitals 
NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT

Tel: 0161 998 7070

PATIENT INFORMATION SHEET

I am planning to do a study about how people cope with life after their transplant. The success of a transplant is not only measured by how much rejection and infection the recipient has, but also the quality of life that they have after the operation and in the future. At this point, I would like to mention that I had a heart and lung transplant in 1994.

What is the title of the study?

AN EXPLORATION OF PSYCHOSOCIAL ADJUSTMENT TO
CARDIOPULMONARY TRANSPLANTATION

Why am I doing this study?

It is important that we have an assessment of the quality of life of recipients, so that we can attempt to help them make the most of their lives in the best way possible and provide services that are needed for the benefit of all.

The information I would like to find out is:

- 1) How a sample of heart and lung transplant recipients aged eighteen to forty at the time of their transplant, cope with life after their transplant?
- 2) How far you live from the hospital, and how long it has been since your transplant.



Chairman - Jeff Wilner Chief Executive - Peter Morris

South Manchester University Hospitals

NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT

Tel: 0161 998 7070

How many volunteers are needed?

My study will need as many transplant recipient volunteers as possible who will need to take some time out to answer the main questionnaire and an extra, small set of questions.

What is the questionnaire like?

There is one main questionnaire and two additional questions on a separate sheet. The main questionnaire asks questions which are specifically designed to look at quality of life, from physical health to emotional reactions and social life. The two extra questions will help me gain a better understanding of your individual experience.

How long will the questionnaire take?

The questionnaire should take approximately 20 minutes to fill in – however, you should take as long as you need for this.

Who can take part in this study?

Any transplant recipient who is prepared to sign the form and give informed consent to take part, and who is between 18-40 years old and who is at least 6 months after their transplant.

What is informed consent?

Informed consent means that you have decided that you are happy to take part in the study and that you feel that you know all about the study and the reasons for doing it before agreeing to take part.



Chairman - Jeff Wilner Chief Executive - Peter Morris

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT

Tel: 0161 998 7070

If you are happy to take part, then please sign the consent form which is included in this letter.

If you would like to ask any further questions before agreeing, or about ANY aspect of the study at any time, then please do feel free to contact me at the transplant unit – it is best if you contact me in writing so that your questions remain confidential and are not seen by anyone else.

What will happen if I decide to take part?

If you decide that you would like to take part, please carefully read the consent form, and sign it where you agree. Then return it back to me as soon as possible in the pre-stamped addressed envelope. I will then send you a copy of the questionnaire and I would ask that you complete it alone, away from family and friends, because it is YOUR quality of life that I am interested in. Your decision to take part will be kept strictly confidential and absolutely no-one else will know that you are taking part.

There is another section on the consent form that allows me to let your GP know that you are doing this study. Again, this is entirely your decision and you do not have to agree to this.

You can take part in this study without your GP knowing.

What will happen if I decide not to take part?

This is YOUR decision, and will be respected. If you decide that you do not wish to take part, then please return the consent form, clearly marking that you do not wish to take part. Your treatment and care at the transplant unit will NOT be affected in any way, and no-one else will know about your decision.



Chairman - Jeff Wilner Chief Executive - Peter Morris

South Manchester University Hospitals

NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT

Tel: 0161 998 7070

How do I contact you?

Feel free to contact me in writing, in a sealed envelope. You can use this address:

HILARY CHEATER
C/o TRANSPLANT UNIT
WYTHENSHAW HOSPITAL
SOUTHMOOR ROAD
MANCHESTER
M23 9LT

PLEASE REMEMBER THAT YOU CAN STOP TAKING PART IN THIS STUDY AT ANY TIME - THERE IS NO PRESSURE UPON YOU TO TAKE PART, AND NO-ONE ELSE WHO WORKS AT THE TRANSPLANT UNIT WILL BE MADE AWARE OF YOUR DECISION TO TAKE PART IN MY STUDY.

THANK YOU



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 8

Consent Form.

South Manchester University Hospitals 
NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT
Tel: 0161 998 7070

CONSENT FORM

**Please read the following options carefully and
only sign by the statements that you agree to.**

I..... (your name in block capitals please)
do/do not wish to take part in this study. (Delete as appropriate)

I am happy for Hilary Cheater to send me the
questionnaire parts of this study for me to complete.

Signature.....

I would/would not like my GP to know that I am taking part
in this study.

Signature.....



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 9

General Practitioner Letter.

South Manchester University Hospitals



NHS Trust

Date

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT
Tel: 0161 998 7070

Dear Dr

I am an MSc student doing my final dissertation research at Wythenshawe Hospital Transplant Unit.

My research is entitled:
"AN EXPLORATION OF PSYCHOSOCIAL ADJUSTMENT TO CARDIO-PULMONARY TRANSPLANTATION"

I would like to let you know that your patient (named below) is taking part in my research

Yours sincerely,

HILARY CHEATER



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 10

'Thank You for Taking Part' letter'.

South Manchester University Hospitals **NHS**
NHS Trust

Wythenshawe Hospital
Southmoor Road
Wythenshawe
Manchester
M23 9LT
Tel: 0161 998 7070

THANK YOU FOR TAKING PART.

Please read carefully and answer ALL of the questions the best you can.

Please answer the questions on your OWN, as it is YOUR experiences that I am interested in.

Don't forget the two additional questions on the separate sheet.

Remember, if you have any questions please feel free to contact me in writing through the Transplant Unit.

Kind regards
Hilary



Chairman - Jeff Wilner Chief Executive - Peter Morris

Appendix 11